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The impact of discrepancies in illness perceptions, between parent and child, in childhood unusual experiences.

Arnold, Rebecca Elizabeth

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VOLUME I

SYSTEMATIC REVIEW AND MAIN RESEARCH PROJECT

Rebecca Arnold

Thesis submitted in partial fulfilment of the degree of Doctorate in Clinical
Psychology

Institute of Psychiatry, Psychology and Neuroscience
King's College, London

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The impact of discrepancies in illness perceptions, between parent and child, in childhood unusual experiences

SYSTEMATIC REVIEW

Illness perceptions in children and young people with mental health conditions: a systematic review

First Supervisor:

Dr Suzanne Jolley, Senior Lecturer and Consultant Clinical Psychologist
Institute of Psychiatry, Psychology & Neuroscience

Second Supervisor:

Dr Juliana Onwumere, Lecturer and Clinical Psychologist
Institute of Psychiatry, Psychology & Neuroscience

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Abstract

Background

An individuals' beliefs about health and illness can have a profound impact on clinical care. In trying to understand variations in illness-related behaviours, research has focused primarily on social cognition models. The Self-Regulation Model (SRM) provides a theoretical framework to help understand how an individuals' conceptualisation of their illness influences coping behaviour and a range of health outcomes. The model proposes that when individuals are faced with a health threat, they develop a set of organised beliefs (illness perceptions) about the illness in terms of five core constructs (identity, timeline, cause, cure/control, and consequences). The principle aim of establishing the applicability of the SRM is to be able to predict how illness perceptions will impact on coping and, with tailored intervention, be adapted for better clinical outcomes. Reviews and meta-analyses across a range of physical illnesses, have demonstrated significant correlations between the SRM dimensions and outcomes. The applicability of this model in a mental health setting has also started to be explored and a systematic review of the adult literature demonstrated that the model was supported in a mental health population. Childhood is a critical period for cognitive and emotional development and a vulnerable period for the onset of mental health difficulties. Understanding illness perceptions in this population is vital considering the evidence of their importance in physical health and growing evidence within the mental health setting for adults. This is the first systematic review to investigate illness perceptions of children and young people (CYP) with mental health conditions in relation to the SRM. This review sought to synthesise a) illness perceptions endorsed by this population, b) the interrelations between illness representation dimensions and c) the relationship between illness perceptions and outcomes.

Method

A comprehensive search of Web of Science, PsycINFO and Medline was undertaken. Studies were assessed for eligibility and the quality of the study rated using established measures. Information pertaining to illness perceptions of CYP with mental health difficulties was extracted and synthesised.

Results

Of 1484 titles, abstracts and full-texts assessed, eight studies met the inclusion criteria, six were cross-sectional and two were qualitative. The findings indicate that the illness perception dimensions, outlined within the SRM, are largely endorsed by CYP experiencing a range of

mental health problems. The studies also provided evidence of associations between illness perceptions and clinical outcomes. In addition, perceptions of stigma were discussed in consideration of further illness representation dimensions, appropriate to this population, which may need to be incorporated to improve applicability of the SRM.

Conclusions

This review is the first to summarise the illness perceptions of CYP with a mental health condition. The findings provide evidence that the SRM was applicable to CYP with mental health conditions and is associated with clinical outcomes in this population. However, due to the methodological issues raised and the small number of studies reviewed, it was not possible to draw firm conclusions. Adaptations to the model may be beneficial within this setting, but further research is needed. Further qualitative research is needed to ensure all illness perceptions reported by this population are addressed by the model. Quantitative research, with improved methodological quality in terms of sample size and selection, and conceptualisation and measurement of both outcomes and IPs, is needed, to rigorously test the use of the illness perception questionnaire (IPQ) and the application of the SRM.

Introduction

Illness Beliefs

Social cognition models are focal in health psychology research as a basis for understanding health related behaviour (Armitage & Conner, 2000). A fundamental principle of the cognitive approach is that individuals make appraisal about their experiences, based on previous learning and experiences, which shape their interpretation of new events (Armitage & Conner, 2000). It is argued, that when an individual experiences an illness, they hold and develop a set of beliefs or 'illness perceptions', about the condition based on their subjective understanding or experience of the condition, which may not necessarily relate to objective clinical symptoms of the illness (Petrie & Weinman, 2006). Patients' illness perceptions have been found to vary widely between individuals, across a number of chronic illnesses, even among individuals with the same condition (Weinman, Petrie, Moss-Morris, & Horne, 1996). This variation is due to illness perceptions being constructed based on a range of factors, such as the patients' knowledge, personal experience and social and cultural factors (Weinman et al., 1996). It is proposed that illness perceptions predict an individuals' response to the health threat, including their engagement in help-seeking and treatment (Weinman et al., 1996). Therefore, understanding how individuals conceptualise their illness may be an avenue for clinical intervention, to improve adherence and ultimately their clinical care and outcomes (Petrie & Weinman, 2006). In physical health, specifically following myocardial infarction, intervening to change illness perceptions has already been shown to improve engagement in treatment and outcomes (Petrie, Cameron, Ellis, Buick, & Weinman, 2002) indicating that it is important that these illness beliefs are explored and addressed. Research utilising social cognition models has attempted to identify the key cognitions in a range of both mental and physical illness. (Lobban, Barrowclough, & Jones, 2003).

Self-Regulation Model

Several different cognitive models propose how health beliefs influence responses to illness. However, of the available models, the Self-Regulation Model (SRM; Leventhal, Nerenz, & Steele, 1984) has been most widely studied as it builds upon previous social cognition models and offers the broadest framework to consider the complexities of chronic illnesses (Weinman et al., 1996).

Leventhal and colleagues initially developed and tested the SRM with studies examining participants' responses to smoking cessation and tetanus immunisations and continued to refine the model with clinical interviews and research with patients with a range of physical health conditions (for review see: Leventhal, Phillips, & Burns, 2016). The model has been given many names as it has been developed and applied across different health areas; such as the Parallel Process Model (Maloney, Lapinski, & Witte, 2011), the Self-Regulatory Model (Petrie & Weinman, 1997), and the Common-Sense Model of self-regulation (Leventhal et al., 2016). For simplicity, it has been referred to as the Self-Regulation Model throughout this review.

The SRM is a hierarchically organized model of an adaptive system, with three main elements: 'representation' of the illness experience, (which guides) action planning or 'coping' responses, (followed by) appraisal or monitoring of the success or failure of coping efforts (Leventhal, 1983). Leventhal (1983) theorised that as people with a chronic illness obtain new information about their condition and evaluate their attempts to cure or cope with its effects, new representations are formed and develop based upon these experiences. The premise is that illness representations are related to coping efforts, and via these efforts to outcomes (Hale, 2007). The SRM stipulates that each individual has both an emotional and cognitive representation of the illness which exist in parallel and jointly influence the individuals' style of coping, their appraisal of how they are coping and subsequently their outcomes (Figure 1) (Leventhal, Leventhal, & Cameron, 2001). Leventhal and colleagues (2001) originally proposed four key constructs/dimensions within the cognitive illness representation. These are, (i) perceived identity of the illness (including a label and signs/symptoms), (ii) perceived consequences of the illness (beliefs regarding the short and long-term physical, social and behavioural effects of the illness), (iii) the likely causes of the illness, and (iv) likely timeline (sense of how long the illness will last). The model has subsequently been developed by Lau and Hartman (1983) to include a fifth cognitive dimension of perceived control or cure (the extent to which the person thinks the illness is modifiable or curable). The SRM proposes that an individual's illness perceptions can be categorised into these dimensions, which can then predict their behavioural and emotional responses, such as the amount of distress, or whether a person will seek or accept treatment, which will in turn influence health outcomes. This process is dynamic, where new information, such as changes in symptoms and appraisals of their coping, are fed back to re-evaluate and refine beliefs which can consequently shift coping patterns, help-seeking behaviour or their

emotional response (Lobban, Barrowclough, & Jones, 2005). The model has been shown to account for a significant amount of variance in illness-related behaviours across a range of physical illnesses, making cognitions an important target for intervention (for review see: Conner & Norman, 2005).

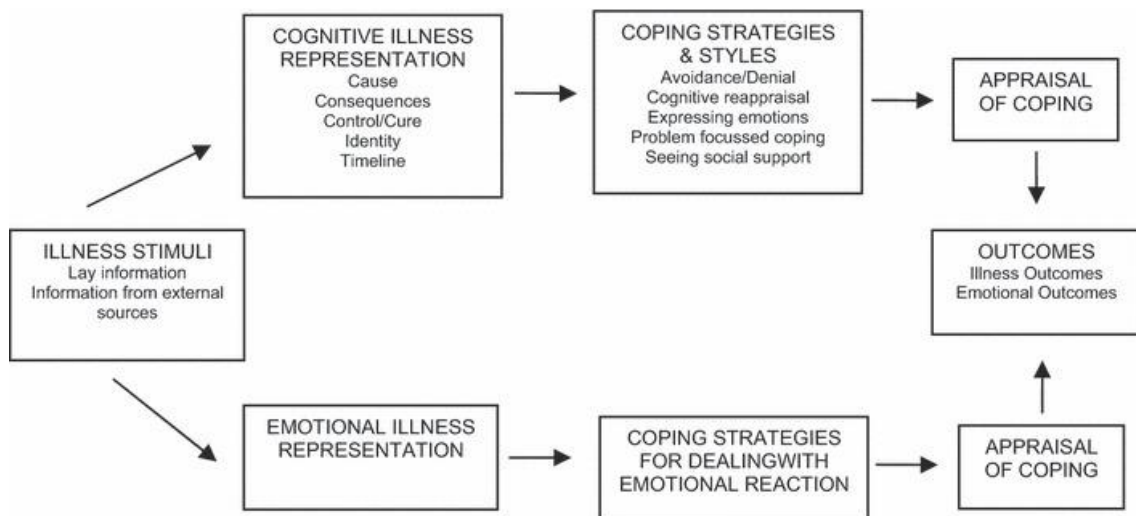


Figure 1. Self- Regulation Model

Measurement of Illness Perceptions

In the early years of illness perception research, assessment of endorsed beliefs was obtained by open-ended interviews, with questions designed to encourage patients to elaborate on their own beliefs about their illness (Petrie & Weinman, 1997). This method produced detailed and informative data but was time consuming and no psychometric data had been produced to support this methodology (Weinman et al., 1996). With the aim of understanding the nature of illness-related coping further and to support development of interventions to facilitate self-management in chronic illness, Weinman and colleagues (1996) developed The 'Illness Perception Questionnaire' (IPQ; Weinman et al., 1996) which was a theoretically-derived measure, based on the SRM dimensions, to assess the illness perceptions within physical health more efficiently and quantitatively but with flexibility to be adapted for specific patient groups or specific health conditions (Weinman et al., 1996). 'The Illness Perception Questionnaire– Revised' (IPQ-R; Moss-Morris et al., 2002) has since been developed to include a new subscale measuring illness coherence (the degree to which a person understands their illness) and has

subdivided the timeline and control subscales. The timeline subscale now distinguishes between acute (symptomatic and curable), cyclic (symptomatic, removable but recurrent) and chronic (a stable part of the self regardless of symptoms) (Leventhal et al., 1984). The control scale has also been separated into two dimensions; treatment control (beliefs about treatment effectiveness) and personal control (perceptions of one's own control over illness and symptom management). In addition to the cognitive representation subscales, the IPQ-R also includes a subscale to assess the emotional representation (awareness of own emotional response to the health threat or symptoms). These adaptations were sought to develop a more comprehensive and psychometrically acceptable scale. A brief version of the IPQ is also available, the 'Brief Illness Perception Questionnaire' (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006), which is composed of a total of nine items addressing the SRM dimensions, offering rapid assessment of illness perceptions, which has been utilised in large-scale studies and in repeated measures research designs. Other developments have included scales for specific illnesses, such as diabetes (Hampson & Glasgow, 1996). The questionnaires provide a quantitative score on each dimension which is suggestive of how the individual understands their illness. For example, high scores on the identity, timeline and consequences dimensions suggest negative beliefs about the number of symptoms attributed to the illness, the consequences of the illness and the chronicity and cyclical nature of the condition, respectively. High scores on the personal control, treatment control and coherence dimensions, indicate positive beliefs about the controllability of the illness and personal understanding of the condition. The IPQ-R has been shown to be a valid, reliable and useful measure of illness beliefs. Broadbent and colleagues (2006) demonstrated that the BIPQ showed good test-retest reliability and concurrent validity with the IPQ-R and good discriminant validity, by its ability to distinguish between different physical illnesses. Adaptations have also been made to produce the Children's Illness Perception Questionnaire (CIPQ) with preliminary evidence of its reliability and validity in CYP with eczema and asthma (Walker, Papadopoulos, Lipton, & Hussein, 2006). These measures enable researchers and clinicians to assess if an individual's illness perceptions influence their outcomes and test the model. This area of research is important for clinical consideration, to determine the impact of illness perceptions on treatment outcomes and potentially adapt them with tailored interventions for improved outcomes.

Physical Health

As discussed, the SRM was originally developed to explain how an individuals' representation of their physical illness experience can influence their coping response and appraisal of coping. The applicability of the model to different physical health conditions has been researched extensively, facilitated by using the IPQ, which was specifically constructed to assess the five components of the SRM (Weinman et al., 1996). Reviews and meta-analyses in adult populations, across a wide range of physical health conditions, have demonstrated significant correlations between the SRM dimensions and outcomes. A meta-analysis by Hagger and Orbell (2003) provided evidence that correlations between illness representation dimensions and illness outcomes were in line with hypotheses based upon the SRM. The meta-analysis consisted of forty-five studies, applying the SRM, of which twenty-three utilised the IPQ or IPQ-R to explore physical illness perceptions. Findings indicated that perceptions of the illness as curable/controllable were significantly and positively related to the adaptive outcomes of psychological well-being and social functioning, and negatively related to psychological distress across physical illnesses. Conversely, negative views of the consequences, timeline and identity of the illness were associated with poorer psychological well-being and social functioning (Hagger & Orbell, 2003).

The clinical applicability of the SRM has continued to be tested, with findings demonstrating negative illness perceptions to be associated with poorer recovery and increased healthcare use in osteoarthritis (Botha-Scheepers et al., 2006) and positive health beliefs prior to cardiac surgery strongly predicting engagement in appropriate health behaviours and better recovery (Juergens, Seekatz, Moosdorf, Petrie, & Rief, 2010).

While much of the extant research has been conducted with adults, there is some evidence that the SRM can be applied to a range of physical health conditions in children and young people (CYP), suggesting that illness perceptions may operate similarly across the lifespan. Law, Tolgyesi and Howard (2014) conducted a systematic review focusing on associations between illness beliefs and specifically, self-management in CYP with chronic physical health conditions. Fifteen studies were eligible for inclusion and within these only certain illness dimensions were explored; the most frequently addressed being 'timeline', 'identity', 'control' and 'consequences'. Whilst there was variability, the results indicated that control beliefs, specifically treatment control beliefs, were more consistently and strongly associated with self-

management than other illness representation dimensions. The findings suggest that CYP who believe that their illness or symptoms can be managed by their treatment are more likely to report engaging in self-management behaviours. This association is in line with the predictions of the SRM and previously reported relationships between perceptions of controllability, active coping and self-care outcomes in adult studies (Hagger & Orbell, 2003; Law et al., 2014). Based on these findings, Law and colleagues (2014) suggest that control beliefs should be a target for intervention in studies trying to improve CYP self-management in physical health. As Hale, Treharne and Kitas (2007) argue, the ultimate goal for health professionals is to determine whether understanding illness perceptions might be able to help predict and potentially adjust certain outcomes for the benefit of the patient. This area of clinical application is in its infancy, but has started to be considered, with Goodman, Morrissey, Graham and Bossingham (2005) conducting a therapeutic trial with individuals with lupus, where the intervention programme contained a module to explain, and attempt to improve, illness beliefs. Their results suggest participants' treatment control perceptions improved and their perceptions of the emotional impact of their lupus and their overall stress reduced.

Mental Health

As the SRM has been demonstrated to be a useful model for understanding physical health illness perceptions and their potential influence on coping and health outcomes, it is understandable that researchers have begun to explore the value of applying the SRM to illness perceptions within mental health. Research exploring illness beliefs within the mental health setting has so far been limited, however, a small number of studies have considered the applicability of illness perceptions in specific mental health conditions, such as; schizophrenia (Lobban, Barrowclough, & Jones, 2004), bipolar disorder (Pollack & Aponte, 2001), anorexia nervosa (Holliday, Wall, Treasure, & Weinman, 2005), personality disorders (Broadbent, Kydd, Sanders, & Vanderpyl, 2008), depression (Bhui, Rudell, & Priebe, 2011; Fortune, Barrowclough, & Lobban, 2004) and anxiety (Bhui et al., 2011).

Lobban, Barrowclough and Jones (2003) systematically reviewed the literature examining the beliefs that people with a mental illness have about their experiences and 59 studies were identified. The review aimed to assess the extent to which these study findings were consistent with the SRM to determine the applicability of the model to mental illness. In relation to the

causal dimension, across the papers, the most commonly identified causes of mental illness were: genetic factors/family history, personality and substance abuse. Individuals who attributed mental health to a physical, medical or biological problem, as opposed to psychological problems, scored higher on measures of perceived quality of life and reported less personal stigma and greater self-esteem (Lobban et al., 2003). In the studies reviewing perceived consequences of symptoms, if seen as high, these were found to negatively influence both coping and mood. Perceptions regarding personal control were found to influence coping styles, outcome and level of emotional distress experienced. Perceived benefits of treatment control were found to be significant predictors of adherence to medication and negative beliefs about psychological treatment resulting in drop out (Lobban et al., 2003). The review of the literature suggests that the dimensions of the SRM are applicable to mental health and that illness perceptions are associated with both coping and outcomes. However, it is noted by the authors that, of the 59 studies reviewed, the majority studied individuals with schizophrenia. Therefore, the results cannot necessarily be generalised to other mental health conditions. Since this review, Baines and Wittkowski (2013) have systematically reviewed studies of the applicability of the SRM within mental health using the IPQ and IPQ-R specifically. Baines and Wittkowski (2013) aimed to assess whether the illness perceptions reported by people with mental health problems were consistent with the SRM dimensions and if they were significantly associated with clinical outcomes. Of the 13 studies reviewed, assessing illness perceptions in psychosis, bipolar disorder, eating disorders and mood disorders, the SRM illness dimensions were largely endorsed. The synthesis of results suggested mental illnesses were commonly viewed as cyclical and chronic, with serious negative consequences. Perceptions regarding chronicity, controllability and negative consequences were associated with coping and help seeking, while engagement with services and help seeking were also related to illness coherence beliefs. Treatment adherence was linked to positive perceptions that treatment could control one's illness and increased personal control perceptions were consistently associated with better outcomes. This is consistent with , Broadbent and colleagues (2008) found that negative illness perceptions were related to poorer attitudes towards medication, and lower functioning. They also reported that more severe symptom perceptions, psychosocial causal attributions, greater concern and higher emotional responses to the illness were associated with more frequent visits to the GP. The authors argue their findings demonstrate interventions targeted at changing illness beliefs may encourage better self-management (Broadbent et al., 2008). The authors of

the IPQ-R suggest that adaptations to the questionnaire may be necessary for different illnesses and research settings (Moss-Morris et al., 2002). In line with this, adaptations to the IPQ-R, to include items for predicting the uptake of cognitive behavioural therapy in psychosis, have been piloted and have been found to be predictive of response to therapy (Marcus et al., 2014).

As in physical health, the majority of studies are with adult populations: only a few studies have considered illness perceptions in younger people. Within the paediatric literature, Haller, Sanci, Sawyer and Patton (2008) systematically reviewed studies examining illness beliefs of young people and how they may affect 'healthcare' outcomes more broadly. They found two different clusters of studies; those that examined concepts of illness in isolation and those that studied relationships between illness beliefs and different aspects of healthcare (e.g. intention to seek healthcare and acceptance of medication/treatment). This review also included research from community samples with no diagnosis and those with a specific diagnosis, consisting of a total of 24 papers. Illness beliefs appeared to play a role in determining help-seeking behaviour and acceptance of care, but results were conflicting on the relationship between illness beliefs and self-management and adherence to treatment. It is important to highlight that within this review, four studies addressed mental health difficulties, however, all of these were a community sample with no diagnosis. Therefore, none of these studies evaluated patients' illness perceptions or the impact of their beliefs on their own outcomes, which would be more clinically valid.

Understanding the illness perceptions of CYP is especially pertinent, due to this stage in life being a critical period in cognitive and emotional development. As the developing behavioural and cognitive systems of the brain mature at different rates, this is a period of increased vulnerability and adjustment (Steinberg, 2005). In the mix of these biological, cognitive and psychosocial changes, CYP are developing their understanding of the world and are forming their foundational cognitive representations, which may result in positive or negative perceptions of illness and therefore result in different behavioural outcomes (Millstein, Petersen, & Nightingale, 1994). Understanding the impact of illness perceptions at this stage and tailoring early intervention could result in long term change due to adapting beliefs before they negatively impact upon help-seeking and clinical outcomes. This approach is in line with international initiatives highlighting the need for earlier interventions; such as the work conducted by the International

Early Psychosis Association and Early Intervention in Mental Health network (e.g. Bertolote & McGorry, 2005) and the World Health Organisation (2013). If understanding young people's illness beliefs could improve clinical outcomes this is an area that demands further understanding.

Applicability of the SRM to Mental Health of CYP

Within the adult literature, there is evidence that the SRM model is applicable in adult mental health and the IPQ and IPQ-R appear to be appropriate measures to assess mental health illness perceptions. However, an issue to consider is whether the SRM dimensions encompass all the illness perceptions that relate to mental health. Kinderman, Setzu, Lobban and Salmon (2006) argue that some of the underlying SRM assumptions may not be relevant or applicable to mental health. Petrie, Broadbent and Kydd (2008) argue the content of illness perceptions in mental illness is less certain than in physical health and although the SRM dimensions have been identified in this population, further constructs may well exist. Lobban, Barrowclough and Jones (2003) emphasise the need to consider potential modifications to the model for its application and understanding within mental health. Petrie, Broadbent and Kydd (2008) highlight that relatively few qualitative studies have been performed to investigate the underlying dimensions of mental illness beliefs, which was the method initially conducted when the model was first applied in physical health, and these may need to be conducted if it appears that the model does not fit mental health conditions.

Systematically reviewing the adult literature has provided a basis of understanding the application of the model in mental health and identifying gaps in knowledge regarding the model's role in understanding mental illness perceptions (Baines & Wittkowski, 2013). However, to date, there is no systematic review examining the role of illness perceptions in CYP with mental health conditions. This would address the applicability of the SRM to this population and synthesise the findings in relation to CYP's beliefs about their own mental health condition. Research is likely to be limited in this field, but to develop our understanding of illness perceptions and the impact of these on outcomes, these findings need to be collated. The importance of reviewing the application of the SRM is further emphasised by the possibility of defining a model that transcends both mental and physical health which could facilitate parity across the specialties. As has been argued, developing psychological theories common to both

physical and mental health could result in an integrated approach and highlight the similarities across illnesses, which in turn could mean mental illness becomes less stigmatised (Lobban et al., 2003).

Aims

Considering the growing evidence of validity for the SRM in both physical and mental health for both adults and CYP and the clinical potential, continuing this area of research is vital. A review of the literature exploring illness perceptions in CYP with mental health conditions would provide a basis of knowledge to understand what the collective findings are to date and establish gaps within the field that require further exploration.

The aims of this review were to:

1. Establish if the SRM is applicable to CYP with a mental health condition by synthesising research investigating:
 - a. The illness perceptions endorsed by this population
 - b. The interrelations between illness representation dimensions
 - c. The relationship between illness perceptions and outcomes.
2. Establish, if possible, if the findings vary across mental health conditions.

Method

Identification of studies

A comprehensive systematic search was conducted identifying the relevant literature. The search strategy consisted of searching electronic databases and reviewing cited articles of sourced papers, as recommended by the Cochrane Collaboration. The databases searched were: PsycINFO, Medline and Web of Science. There were no lower date limits for the searches and primary electronic search ended in August 2016. The search was updated in April 2018 with an additional 152 sources identified. Of these papers, none were eligible for inclusion. The CONSORT diagram reflects the updated results (Figure 2).

The databases were searched with the following search terms within the 'title', 'abstract' and 'key word' fields:

illness representation* OR illness perception* OR illness belief* OR belief* OR personal model* OR symptom representation* OR treatment belief* OR treatment perception* OR self regulat* model OR common-sense model OR schema* AND Pediatric* OR Paediatric* OR Adolescen* OR young people OR young person OR youth OR child* OR teenager* AND mental illness* OR mental health OR mental disorder

These considered the different terms, used interchangeably in the literature, to refer to the key concepts of illness perceptions, the SRM, CYP and mental health. They were based on previous systematic reviews within the field and agreed within the research team. The target papers found in a preliminary ad hoc search were also used to ensure the search terms encompassed these findings and their key words.

Study Selection

Study selection was completed using EndNote X8 following the 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses' guidelines (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009) using the criteria below. A preliminary search suggested limited research in this field was available and therefore the inclusion for this review was wide to ensure the search strategy would return the maximum number of studies that had examined illness perceptions of CYP with mental health conditions.

Inclusion Criteria:

- Study includes a school-age child or young person (age 5-18 years)
- Child has a mental health condition, or is in contact with mental health services
- Child illness perceptions are assessed
- Associations between outcomes and illness perceptions are reported

Exclusion Criteria:

- Present CYP and adult data that cannot be differentiated
- Reporting on psychometric properties of questionnaires only
- Not published in English
- Unpublished findings
- Explored illness perceptions from the perspectives of others (carers, families and professionals)

Quality Assessment

The PRISMA statement (Moher et al., 2009) reports that papers included in a systematic review should be assessed to ensure certain biases do not “hamper the conduct and interpretation of systematic reviews”. To ensure an unbiased selection process, at the eligibility stage a second reviewer independently assessed ten randomly selected papers, to ensure eligibility criteria were followed. The methodological quality of the included studies was appraised independently by two reviewers using the ‘Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies’ developed jointly by methodologists from National Heart, Lung and Blood Institute (NHLBI) and Research Triangle Institute International (2014) and the ‘Critical Appraisal Skills Programme’ (CASP) checklist for qualitative papers (1999). Both tools were designed to assist reviewers in focusing on concepts that are key for critical appraisal of the internal validity of a study. The ratings on the different items were used to assess the risk of bias in the study due to flaws in study design or implementation and to determine if the study is of good, fair or poor quality (NHLBI, 2014). In general terms, a "good" study has the least risk of bias, a "fair" study is susceptible to some bias and this category is likely to be broad, so studies with this rating will vary in their strengths and weaknesses. A "poor" rating indicates significant risk of bias. The measures assess: selection bias; study design; confounders; data collection methods; withdrawals and dropout rates; consideration of missing data and suitability of analysis. The quality rating was considered in relation to result reliability and not used as an exclusion criterion.

Results

Study Identification

In the screening stage, a total of 1845 sources were identified. Following this, duplicate studies, collated from the different databases, were removed (both automatically and manually). At the screening stage, 1602 titles and abstracts were reviewed for inclusion. Based on the inclusion and exclusion criteria, 99 papers required full text review. Of these, 82 papers were excluded for the reasons shown on the CONSORT diagram (figure 2). To be as inclusive as possible, the authors of the seven papers where data could not be differentiated across age, were contacted to see if any analysis had been completed on this age group separately. However, none had reviewed this age group independently. This resulted in a total of eight papers to be included in the review.

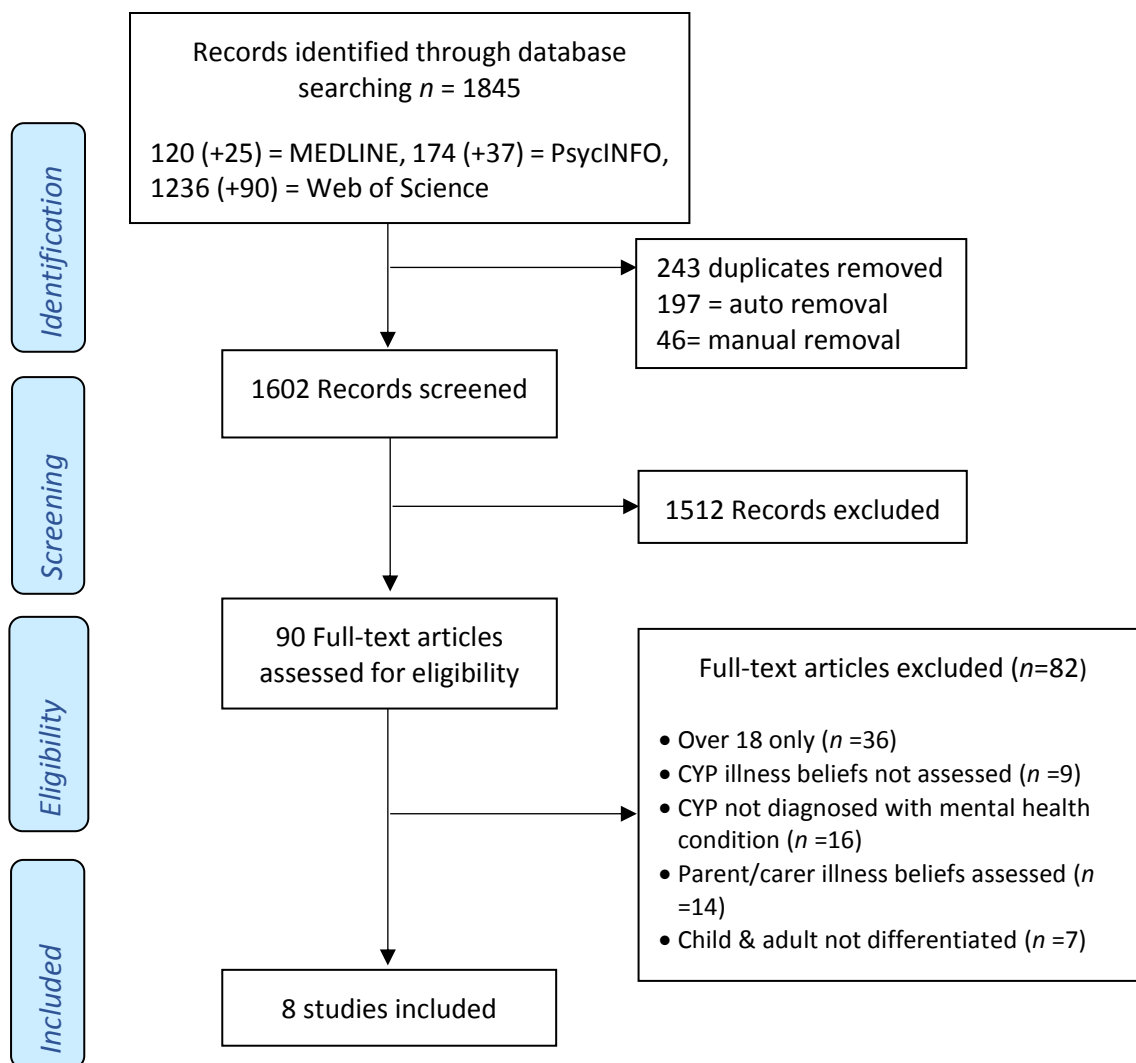


Figure 2. CONSORT diagram

¹(+ n) indicate additional sources identified at update

Quality rating of studies

At the eligibility stage a second reviewer independently assessed ten papers and there was 100% agreement with the first reviewer (RA) on eligibility. With the eight eligible studies, the reviewers compared independent quality ratings assessed using the 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies' and the CASP checklist for qualitative papers. The reviewers had full agreement on the overall level of quality for each paper. On individual items there was some discrepancies noted, however these were discussed and resolved and had no impact on overall rating. As shown in Table 1, two studies were classified as 'poor', five as 'fair' and one study achieved a 'strong' rating. The major limitations that were

associated with an overall 'poor' rating were biases in participant selection (such as period of recruitment and percentage of eligible participation not reported), failure to report sample size justification and lack of consideration of the influence of potential confounding variables.

Table 1. Study Details and quality rating

First author, year & location	Study design	N	Study Aim	Mental Health Condition Explored	Gender	Age	Measures	Analytical Approach	Quality Rating ¹
Imran et al. (2015) Pakistan	CS	52	To assess CYPs' perceptions of their psychiatric illness and the role of various demographic factors in a Pakistani setting.	Axis 1 diagnosis - Conversion disorder with comorbid emotional difficulties 56% Major depression 17.3% Schizophrenia 5.8% Bipolar affective disorder (3.8%) Obsessive -compulsive disorder (5.8%) Generalised anxiety disorder (1.9%) Conduct disorder (1.9%)	67% female	12.7 (SD=2.1) Range: 11-18	Illness Perceptions Questionnaire – Revised (IPQ-R)	Mean scores of IPQ-R subscales & Percentage endorsement of causal items. T test of IPQ-R subcategories & binary variables	Poor
Gaziel et al. (2015) Israel	CS	30	To assess the associations of illness perception-related variables with satisfaction with life among CYPs with mental disorders.	Range of different mental disorders most frequent: Major depressive disorder (n=6) Bipolar (n=5) Disruptive behaviour disorders (n=5) (full break down not provided)	56.6% female	13.9 (1.7 SD) Range: <i>range not reported</i>	Internalised Stigma of Mental Illness Questionnaire (ISMI); Schedule for Assessment of Insight – Expanded (SAI-E); Multidimensional Student's life satisfactions scale (MSLSS)	Pearson's Correlation & Regression	Poor
Munson et al. (2009) Cleveland, USA	CS	70	To assess illness perceptions of CYPs with mood disorders and their attitudes towards seeking mental health services. To establish if these varied due to demographic and clinical	Axis 1 diagnosis and psychotropic medication prescribed or mood disorder diagnosis (bipolar 53%; major depression 44%, substance induced mood disorder 1%; dysthymia 1%)	54% female	15.0 (SD=2) Range: 12-17	IPQ-R; Inventory of Attitudes Towards Seeking Mental Health Services (IASMHS) scale	T tests and Pearson's Correlation	Fair

First author, year & location	Study design	N	Study Aim	Mental Health Condition Explored	Gender	Age	Measures	Analytical Approach	Quality Rating ¹
			characteristics. To explore the relationship between illness perceptions and attitudes and the utility of the Illness Perceptions Questionnaire-Revised (IPQ-R) with CYPs living with a mood disorder.						
Munson et al. (2010) Cleveland, USA	CS	70	To explore the illness perceptions, attitudes towards mental health services and adherence behaviours among a group of CYPs in treatment for mood disorders.	Axis 1 diagnosis and psychotropic medication prescribed or mood disorder diagnosis (bipolar 53%; major depression 44%, substance induced mood disorder 1%; dysthymia 1%)	54% female	15.0 (SD=2) Range: 12-17	IPQ-R; Inventory of Attitudes Towards Seeking Mental Health Services (IASMHS) scale	T tests and Pearson's Correlation	Fair
Moses (2010) Wisconsin, USA	CS	60	To explore CYPs' and parents' perceptions of stigma and perceptions of the cause, controllability, and anticipated outcome (illness perceptions) of CYPs' mental health problems and the extent illness perceptions (CYPs and parents) and parents' own stigma experiences relate to CYPs' self-stigmatization.	70% had at least one affective disorder 71% diagnosed with disruptive behaviour disorder	38.3% female	14.8 (SD=1.6) Range: 12-18	Combination of questions extracted from: Child Stigma Scale; Adolescents Beliefs about Causes Scale; Adolescent's Perceived Controllability Scale; Adolescent's Anticipated Chronicity Scale.	Pearson's Correlation & Regression	Fair
Moses (2015)	CS	10 2	To explore the individual and environmental factors that promote CYPs' use of more/less	68% depression No other statistics reported	63% female	15.3 (SD=1.6) Range:	Semi structured interview: Response to Stress Model and	Pearson's correlations	Fair

First author, year & location	Study design	N	Study Aim	Mental Health Condition Explored	Gender	Age	Measures	Analytical Approach	Quality Rating ¹
Wisconsin, USA			adaptive coping strategies with mental illness stigma. Explore the relationships between anticipated coping and various factors conceptualized as 'coping resource' and 'coping vulnerability' factors.			13-18	measurement tool (RSQ); 'Perceived controllability' & 'Timeline' subscales adapted from IPQ-R; Secrecy Scale.		
Midgley et al. (2017)	Qual	77	To qualitatively explore causal beliefs regarding depression with CYPs referred to mental health service.	Moderate to severe depression diagnosis	71% female	15.86 (SD=1.4) Range: 11-17	Semi structured interview; 'The Expectations of Therapy Interview'	Framework Analysis	Good
Gearing et al. (2014)	Qual	12	To explore youth and parents' changing perceptions of illness in the early course of psychosis to understand the pathways in youth self-determination and self-management of treatment.	Diagnosis of schizophrenia spectrum disorder. [Schizophrenia (N=3), Bipolar (n=5), major depression (n=1) Psychosis NOS (n=2)]	50% female	16.2 (SD=1.2) at admission Range 13-17			Fair

CS = Cross sectional design, Qual = Qualitative design, UK = United Kingdom, USA = United States of America, SD = Standard Deviation, CYP = Children and Young People

¹Quality rating calculated using the 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies' (CITE) and the 'Critical Appraisal Skills Programme' (CASP) checklist for qualitative papers.

Table 2. Summary of illness perceptions assessed and findings

First Author, Year	SRM discussed	IPQ/IPQ-R used	SRM Constructs Applied	Other constructs reported	Findings
Imran et al. (2015)	No	Yes	Timeline Consequences Cause Control Identity (illness coherence) Emotional - Representation	-	<p>Sample perceived illness to be chronic ($M = 16.4$, $SD = 2.2$) and cyclical ($M = 11.0$, $SD = 2.2$). Significant negative consequences as result of mental health difficulties ($M = 17.5$, $SD = 2.4$) and negative emotional response observed ($M = 16.2$, $SD = 3.5$).</p> <p>Perception of personal control over illness ($M = 18.8$, $SD = 2.2$) and positive belief in treatment role ($M = 12.6$, $SD = 3.2$). CYPs felt had a coherent model/understanding of their illness ($M = 14.8$, $SD = 2.2$)</p> <p>Males significantly higher scores on <i>timeline</i> ($t = 17.5$ (2.4), $p < 0.05$) and <i>emotional representation</i> ($t = 17.8$ (3.4), $p < 0.05$)</p> <p>Patients living in nuclear family set up had better beliefs about controllability of illness than those living in joint/extended family system ($t = 13.8$ (3.0), $p < 0.05$)</p> <p>Participants endorsed psychological and personal factors as causal more than genetic or immunological causes. Rated high: Own emotional state (46%), stress (40%), family problems (39%), personality (35%), past medical care (40%) and bad luck (39%) versus Hereditary (13%), immunity (12%). Discussion of cultural differences related to Munson (2009) findings.</p>
Gaziel et al. (2015)	No	No	Identity	Self-Stigma	<p>Significant negative correlation found between CYP insight into disorder and satisfaction with life ($r = -0.600$, $p < 0.05$).</p> <p>Negative correlation between self-stigma and satisfaction with life ($r = 0.374$, $p < 0.05$).</p> <p>Positive correlation found between CYP's insight and self-stigma ($r = 0.386$, $p < 0.05$). Reported participants with higher insight into disorder have higher self-stigma and lower Satisfaction with life than those who report less insight.</p>
Munson et al. (2009)	Yes	Yes	Timeline Consequences Cause Control Identity Emotional - Representation	-	<p>Positive attitudes towards mental health services ($M = 60.1$, $SD = 12.3$). Propensity to seek help ($M = 21.4$, $SD = 5.6$) and indifference to stigma ($M = 20.9$, $SD = 6.3$). Suggested majority had positive attitudes towards seeking professional help.</p> <p>Majority of sample perceived illness to be chronic ($M = 13.6$, $SD = 5.9$) and have major consequences on life ($M = 13.4$, $SD = 5.7$).</p> <p><i>Small group perceived</i> disorder to be cyclical ($M = 8.6$, $SD = 3.5$) and even fewer associated emotional representations to mental health ($M = 105$, $SD = 5.8$). (Only means given not percentages of sample so quantity NR).</p> <p>Perception of personal control ($M = 15.3$, $SD = 4.6$) and treatment control ($M = 13.1$, $SD = 3.5$).</p> <p>Reported over 50% strongly agreed or agreed that their own actions and treatments that exist can influence or control whether they get better. Illness coherence ($M = 12.7$, $SD = 5.1$)</p>

First Author, Year	SRM discussed	IPQ/IPQ-R used	SRM Constructs Applied	Other constructs reported	Findings
					<p>Negative correlation between <i>timeline</i> and <i>personal control</i> ($r=-0.20, p<0.1$) and <i>treatment control</i> ($r=-0.29, p<0.05$) observed. Suggested the more participants perceived mental health to be chronic the less they perceived control of symptoms.</p> <p>Participants reporting higher emotional representations related to indifference in stigma ($r=-0.49, p<0.0001$).</p> <p>Illness coherence positively correlated to openness towards professional help ($r=0.29, p<0.05$) and indifference to stigma ($r=0.40, p<0.0001$). 'Youth of colour' reported significantly lower scores on the indifference to stigma subscale ($\beta = -3.39, SE = 1.64, t = -2.06^*$).</p>
Munson et al. (2010)	Yes	Yes	Consequences Control Emotional – Representation	-	<p>Relationships between attitudes towards professional psychology services and adherence. 63% reported taking prescribed medications all the time and 73% reported full adherence to mental health appointments. Participants reporting full adherence to mental health appointments reporting more positive attitudes towards services ($t=5.33, p<0.05$). Illness perceptions associated with adherence, participants reporting full adherence to mental health appointments reporting higher scores on consequences sub scale (perceived mental health to have serious consequences on life, compared to not fully adherent group) ($t=4.34, p<0.05$). Fully adherent group reported higher levels of emotional reactions to mood disorder than those not fully adherent ($t=2.87, p<0.10$).</p>
Moses (2010)	Yes	No	Timeline Cause Control	Self-Stigma	<p>Participants most commonly endorsed personality (62%) as causal factor. Trauma (53%), family problems (48%), biological causes (47%) and social problems (skill deficits; 32%) also endorsed as causal factors. Economic problems least likely to be endorsed (20%).</p> <p>Perceived ability to control negative emotions and behaviours (personal control) ($M=3.5, SD=0.66$) and experience mental health problems for rest of life (chronicity) ($M=2.7, SD=1.2$)</p> <p>Illness perceptions significantly associated with self-stigma rating (<i>no global correlation score, significant correlations to individual items</i>). Positive correlation between chronicity and self-stigma ($r=0.35, p<0.01$), negative correlation between controllability and self-stigma ($r=-0.28, p<0.05$) CYP's scoring higher on chronicity and lower on personal control, scored higher on self-stigma. Endorsement of more causal factors correlated with higher ratings on self-stigma ($r=0.60, p<0.001$)</p>
Moses (2015)	No	Some items	Timeline Control	-	<p>Relationship between perceived controllability and 'expected short-term' (stability/chronicity) ($r=0.55, p<0.001$), self-esteem ($r=0.51, p<0.001$). Negative relationship between perceived controllability and youth self-reported internalising problems (clinical symptoms) ($r=-0.53, p<0.001$). 'Expected short-term' (stability/ chronicity) negative relationship with both self-reported internalising and externalising problems ($r=-0.46, p<0.001$; $r=-0.41, p<0.001$).</p> <p>Coping resource factors reported as optimistic illness perceptions and positive perceptions of treatment. No significant difference in age or gender found.</p>

First Author, Year	SRM discussed	IPQ/IPQ-R used	SRM Constructs Applied	Other constructs reported	Findings
Midgley et al. (2017)	No	N/A	Cause Identity	-	<p>Causal focus - Three themes:</p> <ul style="list-style-type: none"> - “Bewilderment about why depressed” ‘Many’ (reported as 33-59/70 participants) struggled to respond when asked how understood their difficulties. (<i>Relates to Identity & mental health coherence subscales</i>) - “Result of rejections, victimisation and stress” – ‘Many’ associated onset of difficulties with stressful experiences. (<i>relates to cause subscale</i>) -Internal “something inside is to blame” ‘Some’ (reported as 15-27/70) saw their difficulties coming from within or part of who they are. ‘Some’ offered genetic explanation A few (less than 14/70) offered biological explanations (<i>relates to cause and cure/control subscale</i>)
Gearing et al. (2014)	No	N/A	Timeline Cause Control Identity Emotional - Representation	-	<p>Interviews completed 3 years after discharge.</p> <p>Focus - changes to illness perceptions over stages of illness from CYP & parent perspective. Themes (from CYP only) include; negative self-perceptions (n=3) “I was like just really lazy minded” and negative appraisals endorsed of fear (n=9) and hopelessness (n=2).</p> <p>66% (n=8) reported acceptance of illness in self at hospitalisation stage. n=4 endorsed emergence of coping skills. At ‘current phase’ 67% (n=8) endorsed integrating illness into identity “I have accepted the fact I have like an illness or whatever and can deal with it and it really doesn’t bother me”. Another dominant theme taking responsibility for own treatment (58%, n=7) “it is great I am on medications”.</p> <p>N=4 identified positive effects of experience and improved coping skills.</p> <p>Functional plans endorsed for future, 75% (n=9) “future could be bright as long as I continue to be healthy and take care of myself”. N=6 discussed future treatment plans.</p> <p>No causal attributions made by CYPs reported however one quote for integration into identity “as I got to know more about my illness and realised that schizophrenia is a mental illness, a chemical imbalance of the brain”.</p>

CYP = Children and Young People, M = Mean, SD = Standard Deviation, N/A = not applicable, p = significance value.

Overview

Study Characteristics

Of the eight studies included, there were seven unique data sets. One author (Munson, Floersch, & Townsend, 2009, 2010) used the same clinical sample to examine different data and findings. The majority of studies were conducted in the USA (n=5), the others were conducted in Pakistan, Israel and the England. The age range, across the seven studies that reported it, was 11-18 years. Sample size varied from 12 to 102 participants across studies. Six of the papers were quantitative and two were qualitative, all were cross sectional. The aims of the different studies were broad and highlighted the mixed approach to studying illness perceptions within this population currently. The details of the individual papers including their individual aims, are reported in Table 1 and the findings supported by the statistical information are reported in Table 2.

SRM & Illness Perceptions

Of the eight papers, only two (Munson et al., 2009, 2010) discussed the applicability of the SRM directly to mental health conditions, utilising the IPQ-R. Imran, Azeem, Chaudhry, and Butt (2015) discussed the use of the illness representation dimensions (and used the IPQ-R) but did not examine the use of the SRM itself. Moses (2010) discussed the use of the SRM but used a range of other measures to assess illness perceptions. Moses (2015) used some of the subscales of the IPQ-R, however without reference to the SRM. Gaziel et al. (2015) discussed 'insight' which the paper defined as "awareness of the disorder's label, the need for treatment, and of the disorder's implications". Midgley et al. (2017) qualitatively explored causal beliefs with no reference to the SRM and finally, Gearing et al. (2014) qualitatively explored perceptions of illness through phases of early psychosis retrospectively. With the papers that did not directly quantify the findings within the SRM, the current review has determined which dimension the findings are associated with, or if not suitable, whether there are other illness perceptions that if they should be considered as a separate construct (Table 2). The findings reported, across the papers, differed in how they assessed illness beliefs, with some evaluating the endorsement of an illness representation dimension by the sample (often using mean differences), others referencing endorsement of statements/single items and others reporting correlations between illness representation dimensions and outcomes. Due to the variation in methodology,

descriptive synthesis has been used and the findings detailed in order of the review aims.

Measurement of Illness Perceptions

The terms used to describe illness perceptions vary within the literature, with the selected papers using descriptions such as; illness beliefs, illness perceptions, insight and health beliefs. The method of measuring illness perceptions also varied across the six quantitative studies. Munson et al., (2009; 2010) and Imran et al., (2015) used an unaltered IPQ-R; Gaziel et al. (2015) used the 'Internalised Stigma of Mental Illness Questionnaire' (ISMI) and the 'Schedule for Assessment of Insight – Expanded' (SAI-E); Moses (2010) used a combination of questions extracted from: the 'Child Stigma Scale', 'Adolescents Beliefs about Causes Scale', 'Adolescent's Perceived Controllability Scale', and the 'Adolescent's Anticipated Chronicity Scale'; and finally, Moses (2015) used a combination of 'Response to Stress Model and measurement tool' (RSQ), 'Perceived controllability' & 'Timeline' subscales adapted from IPQ-R and the 'Secrecy Scale'.

Aim 1) Establishing if the SRM constructs are applicable to young people with a mental health condition

The main aim of the review was to establish if the SRM constructs were applicable to CYP with a mental health condition by synthesising a) illness perceptions endorsed by this population, b) the interrelations between illness representation dimensions and c) the relationship between illness perceptions and outcomes. The findings have been synthesised in relation to the SRM dimensions; identity, timeline, cause, control and emotional representation. Any other findings within the papers that may suggest other illness representation constructs for this population are also included.

Illness perceptions endorsed by this population

Identity

The identity dimension of the SRM assesses what the individual thinks the problem is, including the signs and symptoms experienced by individuals and the label that they give to these (Lobban et al., 2003). Coherence, as measured on the IPQ-R is a measure of the Identity dimension (Moss-Morris et al., 2002). Five papers report findings that relate to the identity dimension.

Both Imran et al., (2015) and Munson et al., (2009) reported mean scores on the IPQ-R illness coherence subscale, of 14.8 (SD=2.2) and 12.7 (SD=5.1), respectively. This suggests that their samples reported a coherent understanding of their illness, with the sample in Imran et al. (2015)

reporting a poorer mental health understanding regarding the nature, treatment and prognosis on average than the sample in Munson et al. (2009). Certain findings within the qualitative papers corresponded with the identity representation. Gearing et al. (2014) found that 67% (n=8) of participants endorsed the theme 'integrating their illness into their identity' with quotes such as; "I have accepted the fact I have like an illness or whatever and can deal with it and it really doesn't bother me". However, it could also be argued that this statement is suggestive of personal control and emotional representation. Midgley et al. (2017) collated a theme of "bewilderment about why depression" as they reported that young people struggle to make sense of why they feel different from others and where their depression has come from, with 'many' participants (reported as 33-59/70 participants) struggling to respond when asked how they understood their difficulties. Midgley et al. (2017) reported that giving meaning to one's experiences was an important part of creating sense of order and re-establishing identity.

Timeline

The timeline dimension categorises patients' expectations into three categories; acute (symptomatic and curable), cyclic (symptomatic, removable but recurrent) and chronic (a stable part of the self regardless of symptoms) (Leventhal et al., 1984). This dimension was reported in five of the papers.

Imran et al. (2015) reported that the overall sample perceived their illness as chronic and cyclical, as shown with a reported above average mean of 16.4 (in a range of 0-30) on the chronicity items. Munson et al. (2009) also reported that "over 50%" of sample perceived their illness to be chronic, with a mean of 13.6 (range of 0-24) and "a small group" perceived disorder to be cyclical, however, the number of individuals endorsing these were not reported. Moses (2010) reported that 42% of participants believed they would experience mental health problems for the rest of their life. Imran et al. (2015) also analysed demographic differences and found males scored higher, suggesting stronger beliefs about chronicity than females. Gearing et al. (2014) reported a positive outlook on chronicity, with 75% (n=9) agreeing that the "future could be bright as long as I continue to be healthy and take care of myself".

Consequences

The consequences dimension assesses what influence individuals believe having mental health problems will have for their lives (the short and long-term impact of illness on the physical, psychological and social well-being of self and others)(Lobban et al., 2003). This dimension was reported in three of the papers, two in relation to endorsement. Both Imran et al. (2015) and

Munson et al. (2009) reported that participants perceived significant negative consequences as a result of their mental health difficulties.

Cause

The cause dimension encompasses factors the individual perceived to cause illness, e.g., genes or infection (Lobban et al., 2003). This dimension was discussed by six of the included studies. Across the studies, personal and psychological factors were endorsed more than biological or genetic factors. Imran et al. (2015) reported that participants endorsed psychological and personal factors as causal more than genetic or immunological causes. The factors most commonly endorsed were; own emotional state (46%), stress (40%), family problems (39%), personality (35%), past medical care (40%) and bad luck (39%) versus hereditary (13%) and immunology (12%) which were the least endorsed. Moses (2010) had a much higher endorsement of personality factors (62%) with trauma (53%), family problems (48%), biological causes (47%) and social problems (e.g. skill deficits; 32%) also reported and economic problems the least endorsed (20%) causal factor.

Midgley et al. (2017) had a theme of “Result of rejections, victimisation and stress”, with ‘many’ participants (reported as 33-59/70) associating onset of difficulties with stressful experiences. Participants attributed difficulties to range of stressful experiences, with a focus on exam/education stress. ‘Some’ participants ($n=15-27/70$) saw their difficulties as coming from within or part of who they are, which was themed as “something inside is to blame”. However, ‘some’ ($n=15/27/70$) participants also offered a genetic explanation and a ‘few’ (less than 14/70) offered biological explanations. Gearing et al. (2014) stated that no causal attributions were made by CYPs, however, one quote for the theme ‘integration into identity’ is suggestive of a perception of a biological explanation; “as I got to know more about my illness and realised that schizophrenia is a mental illness, a chemical imbalance of the brain”.

Control/Cure

The control dimension assesses the extent to which the person believes the condition to be amenable to cure or control (Barrowclough, Lobban, Hatton, & Quinn, 2001). The control dimension was subdivided when the ‘The Illness Perception Questionnaire–Revised’ (IPQ-R; Moss-Morris et al., 2002) was developed, into treatment control (beliefs about treatment effectiveness) and personal control (perceptions of ones’ own control over illness and symptom

management). Six of the papers explored aspects of the control dimension, which are presented within the two subdimensions.

Treatment Control

Munson et al. (2009) reported participants had positive attitudes towards mental health services, in particular, a propensity to seek help. They reported 54% agreed treatments can influence, or control, whether they get better, however this is only just a majority. Imran et al. (2015) reported participants had positive beliefs in the role of treatment, with a mean of 11.1 and a range of 0-20. However, again this is only just above average. Within the qualitative interviews, Gearing et al. (2014) reported a dominant theme of 'taking responsibility for own treatment' was observed, with 58% (n=7) endorsing "it is great I am on medications".

Personal Control

Both Imran et al. (2015) and Munson et al. (2009) reported individuals had a perception of personal control over illness, with Munson et al. (2009) reporting that over 50% strongly agreed or agreed that their own actions can influence or control whether they get better. However, no percentages of participants endorsing these items were reported. Moses (2010) reported participants perceived an ability to control negative emotions and behaviours.

Emotional Representation

The SRM proposes that in response to an illness, in parallel with the cognitive perceptions, people develop emotional representations. The IPQ-R addresses this dimension by exploring an individuals' awareness of their own emotional reactions to the health threat. This dimension was reported in four of the papers, the three papers utilising the IPQ-R and some qualitative responses from Gearing et al. (2014) that can be defined as emotional representation. Imran et al. (2015) observed a negative emotional response reported across the sample, with males scoring higher. This suggests males held stronger anger and worry towards their condition than females. No other papers reported gender differences. Munson et al. (2009) described that a "few" participants associated negative emotional perceptions to their mental health condition, however, the number of participants endorsing this was not reported.

Other Dimensions

Considering illness perceptions have not been examined extensively in this population, as they have been in physical health, there is the possibility of illness perceptions expressed by CYP with

mental health conditions, not being encapsulated in the current constructs of the SRM. Within the small sample of studies, three papers reported results on perceptions of self-stigma; a construct that could be thought of as a distinct illness representation. Moses (2010) referred to 'self-stigma' in this context as individuals who were "socialized to relate to mental illness negatively, applying negative cultural stereotypes about mental illness to themselves in a way that generates negative reactions including shame, secrecy, fear, and anticipation of being rejected and discriminated against by others, as well as lowered self-esteem or self-efficacy". In his later paper, Moses (2015) used a 'hypothetical social stigma scenario' to elicit coping strategies, therefore instigating an action/outcome. Munson et al. (2009) reported stigma as an 'attitude' towards seeking help, which would suggest an evaluative component (prejudice). These different conceptualisations of stigma highlight the various ways stigma can be perceived. Within this review the results are reported with the possibility of stigma being a further illness representation construct and the evidence for this discussed. The studies reviewed reported stigma as an outcome and therefore only one endorsement related to stigma was discussed. Munson et al. (2009) reported that a majority of participants felt indifferent to stigma, in relation to how people would react to them seeking help.

The interrelations between illness representation dimensions

None of the papers considered associations between the identity, consequences, cause or emotional dimensions, only associations between timeline and control were analysed. Stigma was examined in relation to identity, timeline and control. Munson et al. (2009) reported a negative correlation between timeline and both personal and treatment control; suggesting the more an individual perceived their mental health condition to be chronic the less likely they were to perceive personal control over symptoms or believe treatment could improve their condition. Similarly, Moses (2015) found a correlation between perceived controllability and 'expected short-term' (timeline), such that CYPs perceiving increased control reported a perception of a shorter timeline of emotional and behavioural problems. Munson et al. (2009) also reported a positive association between personal and treatment control, as CYPs with greater perceived personal control on their mood were more likely to believe treatment could control their disorder.

Moses (2010) found a negative correlation between control and self-stigma, suggesting individuals who perceived less personal control and anticipated mental health problems to be

lifelong scored higher on self-stigma. Moses (2010) reported a positive correlation between chronicity and self-stigma; with individuals who perceived illness to be more chronic reporting higher self-stigma. Munson et al. (2009) reported a positive association between level of stigma and perceived consequences and emotional reaction meaning higher emotional responses to mood disorders and larger perceived consequences were associated with greater experienced stigma. Moses (2010) reported endorsement of more causal factors correlated with higher self-stigma.

Gaziel et al. (2015) reported a positive correlation between CYP's insight (coherence) and self-stigma, demonstrating that participants who reported higher insight into their disorder had higher self-stigma than those who reported less insight. These findings contradict that of Munson et al. (2009) who found that illness coherence positively correlated to indifference to stigma, suggesting the more coherent understanding CYPs had regarding their illness, the less influenced they were by stigma.

The relationship between illness perceptions and outcomes

Identity

Munson et al. (2009) found that illness coherence positively correlated to openness towards professional help, suggesting the more coherent understanding CYPs had regarding their illness, the more open they were to receiving professional support. Gaziel et al. (2015) found a significant negative correlation between CYP insight into their mental health condition and satisfaction with life, such that CYP's with greater insight reported lower satisfaction. This suggests that having insight into one's illness is associated with poorer life satisfaction. Gearing et al. (2014) found 66% (n=8) participants reported acceptance of their illness when hospitalised with their mental health condition and four of these individuals endorsed an emergence of coping skills at this stage, suggesting a possible association between illness acceptance and coping.

Timeline

Moses (2015) reported a positive correlation between timeline and coping; with individuals endorsing expectations of a 'short illness timeline' utilising more engaged and positive coping strategies. Moses (2015) also reported a negative relationship between timeline and internalising and externalising problems (such as withdrawal, somatic complaints and

anxiety/depression and aggressive or delinquent behaviour) as reported by the CYP. Both findings indicate that perceiving mental health difficulties as enduring was associated with an increase in reported problems and less coping strategies.

Consequences

Munson et al. (2010) reported a relationship between adherence and the consequences dimension, with participants who reported full adherence to their mental health appointments also reporting higher perceived negative consequences as a result of their mental health condition, compared to the nonadherent group. This implies that CYP who perceive there to be more negative consequences are more likely to adhere to treatment.

Cause

No relationships between causal attributions and outcomes were examined.

Treatment control

Munson et al. (2010) found that attitudes towards psychological services was significantly related to adherence, with participants reporting more positive attitudes towards services having full adherence to mental health appointments. Imran et al. (2015) considered the influence of demographic factors and found patients who are from a nuclear family set up had more positive beliefs about controllability of illness than those living in a joint/extended family system.

Personal control

The associations between personal control and outcomes was only examined by Moses (2010), who reported several correlations. A negative relationship between perceived controllability and internalising problems (such as withdrawal, somatic complaints and anxiety/depression) and a positive relationship between perceived controllability of symptoms and positive coping strategies and with self-esteem. Both suggesting increased perceptions of personal control is associated with less internalising problems, increased coping strategies and higher self-esteem.

Emotional Representation

Munson et al. (2010) found an association between emotional representation and adherence, the fully adherent group (in relation to mental health appointments) reported higher levels of emotional reaction to their mood disorder than the nonadherent group. This implies that expressing higher levels of negative emotion is associated with higher levels of treatment adherence. Gearing et al. (2014) reported themes that could be considered emotional perceptions, with CYPs (n=3) endorsing negative self-perceptions, such as “I was like just really lazy minded” and negative appraisals of fear (n=9) and hopelessness (n=2) endorsed.

Stigma

Moses (2010) found a correlation between self-stigma and coping, with less self-stigma being associated with a greater use of coping strategies. Gaziol et al. (2015) reported a negative correlation between self-stigma and satisfaction with life, with participants who reported higher self-stigma also reporting poorer life satisfaction.

Aim 2) Establish if the findings vary across mental health conditions.

The second aim was to establish, if possible, if the findings vary across mental health conditions. Four papers focused on specific conditions; Munson et al. (2009; 2010) recruited participants with a mood disorder diagnosis, Midgley et al. (2017) recruited participants with a diagnosis of depression and Gearing et al. (2014) recruited participants with a diagnosis of psychosis. The other four papers recruited participants who had any Axis 1 diagnosis which included schizophrenia, bipolar affective disorder, obsessive-compulsive disorder, generalised anxiety disorder and conduct disorder, with a majority reporting depression as the most frequent diagnosis. However, due to the heterogeneity of mental health conditions and limited findings, the results have not been compared across mental health conditions. It is of note, however, that there were commonalities across mental health conditions, such that all IP dimensions were applied and identified to some extent within all disorders studied.

Discussion

The aims of this review were to 1) establish if the SRM constructs were applicable to CYP with mental health conditions and if so, what illness perceptions were endorsed in this population and what relationship these dimensions had to one another and outcomes and 2) establish, if possible, if the findings vary across mental health conditions. A total of eight papers met the inclusion criteria for the review, highlighting the limited research in this field. However, the findings reviewed went some way to explaining the applicability of the SRM model and signposted the gaps in knowledge which need further investigation.

Establishing if the SRM constructs are applicable to young people with a mental health condition

The number of papers that have researched this area was small, and therefore assessment of the applicability of the model based on these eight papers is restricted. In summary, three of the eight papers explicitly applied the SRM to CYP with a mental health condition (Moses, 2010; Munson et al., 2009, 2010). Four papers utilised the IPQ-R (in part or full), a questionnaire

designed on the SRM constructs, to test illness perceptions (Imran et al., 2015; Munson et al., 2009, 2010). The other three papers refer to illness perceptions that map onto the dimensions represented in the SRM. One referring to 'insight' into the illness, with data that relates to the consequences and cause dimensions (Gaziel et al., 2015) and two that have used qualitative methods to explore causal beliefs (Midgley et al., 2017) and perceptions of illness through phases of early psychosis (Gearing et al., 2014). Despite the small literature sample, the findings suggest that the SRM is applicable to CYP people with mental health conditions as the illness perceptions outlined within the SRM were largely endorsed within the clinical samples studied. All five of the cognitive illness perceptions and the emotional representation were reported on, to some degree, across the eight papers.

Illness Perceptions endorsed

It was encouraging that participants reported a coherent understanding of their mental health (Imran et al., 2015; Munson et al., 2009), especially when associated with life satisfaction and coping skills (Gaziel et al., 2015; Gearing et al., 2014). Both Imran et al. (2015) and Munson et al. (2009) reported that a majority of participants viewed their mental health condition as chronic and cyclical, however, it appears that this was endorsed by just over half of participants and Moses (2010) reported 42% of participants endorsed their mental health condition as chronic. In comparison with the adult literature of mental health illness perceptions, both adults and CYP endorsed mental health difficulties as being chronic with serious negative consequences. However, the percentages across CYP studies suggest that this is only marginally a majority, which is encouraging as it suggests this perception is not universally endorsed by CYP. However, interestingly, the perception of chronicity was associated with engagement in treatment (Moses, 2010; Munson et al., 2009). With chronicity not yet being a strongly held belief and associated with engagement, this highlights a key illness perception to address and modify, especially as perceptions that mental health difficulties would be temporary/short-lived was associated with improved coping and fewer reported internalising and externalising problems (such as withdrawal, somatic complaints and anxiety/depression and aggressive or delinquent behaviour)(Moses, 2015). A majority of participants perceived significant negative consequences as a result of their mental health (Imran et al., 2015; Munson et al., 2009) and an association between consequences and adherence suggests perceptions of how difficulties are impacting upon life influences adherence to treatment (Munson et al., 2010). Within the adult literature,

perceptions of mental health as having negative consequences were associated with seeking help. Addressing these IPs at an earlier age could improve engagement across the lifespan. Psychological and personal causes were endorsed more than genetic/biological causes, with 35-62% of participants endorsing personality as cause of mental health difficulties (Imran et al., 2015; Moses, 2010). Midgley et al. (2017) reported 'many' participants associating onset of mental health with stressful experiences, in particular exam and education stress. This finding is reinforced with 40% of participants endorsing stress as a cause in the study by Imran et al. (2015). These findings link with previous evidence of stressful life events being a risk factor for mental health difficulties (Colten, 2017). The findings emphasize that intervention addressing stress-coping strategies for CYP would be beneficial in reducing the risk of later mental health difficulties and distress (Chou, Ko, Hsiao, Cheng, & Yen, 2017). The causal attributions of CYP were consistent with commonly endorsed causes of mental illness within the adult studies such as stress, personality and genetic factors, but a smaller proportion of CYP endorsed genetic factors. There was variance across the studies in the levels of participants endorsing biological and hereditary causes, a factor which may be more relevant within CYP mental health compared to physical health conditions. Rather than specific causes relating to outcomes, a relationship was found between the number of causal factors endorsed and levels of self-stigma (Moses, 2010). Supporting CYP to understand the potential causes of mental health and reduce the self-blame, often associated with beliefs of personality as the cause, could lead to improvements in self-stigma and help seeking. Despite a majority endorsing internal causes, participants also perceived personal control over their symptoms, with over 50% agreeing they can control if they get better (Munson et al., 2009). This is a promising protective factor, as lower levels of personal control endorsed has previously been associated with higher distress (Hagger & Orbell, 2003). Participants reported a positive attitude towards mental health services (Imran et al., 2015; Munson et al., 2009), with over 50% agreeing treatment can influence outcomes and 58% of participants endorsing medication as positive (Gearing et al., 2014). Consistent with the adult literature, positive attitudes towards mental health services was associated with adherence to treatment (Lobban et al., 2003). High levels of perceived personal control were associated with less reported internalising problems, and better coping and self-esteem (Moses, 2015). Imran, et al., (2015) observed a gender difference within their sample, with males reporting a more chronic perception of mental health and a more negative emotional response, however no other studies explored gender differences.

Overall the studies provide evidence of the SRM being applicable to CYP with mental health conditions, reported associations between illness perceptions endorsed and a broad range of outcomes. These findings were consistent with the conclusions made by Baines and Wittkowski (2013) that the SRM dimensions were applicable to an adult population experiencing mental health difficulties and were associated with outcomes and coping. These results combined suggest the SRM is applicable within mental health conditions. These results support the argument for therapeutic interventions to address and adapt illness perceptions in an attempt to improve clinical outcomes and adherence to treatment. Despite this support for the model, there were other considerations that may challenge its direct application to this population.

[Challenges to the applicability of the SRM in this population](#)

Kinderman, Setzu, Lobban and Salmon (2006) argued that some of the underlying SRM assumptions are not applicable to mental health. In particular, some research studies have suggested that individuals' beliefs regarding mental illnesses may not be stable over time and more changeable than in physical health. This fluctuation is reflected in the current findings, with changes to illness perceptions endorsed by young people at different stages following admission (Gearing et al., 2014). This fluidity is to be expected as it likely reflects the changeable nature of mental health problems and possibly enhances the potential for illness perceptions to be adapted with intervention.

A consideration within this review was the possibility of CYP with mental health conditions endorsing other illness perceptions not encapsulated within the current SRM model. A benefit of including qualitative studies in this review was the possibility of broadening the illness perceptions reported. For example, (Midgley et al., 2017) reported the theme of "bewilderment about why depression" which was deemed relatable to the identity illness perceptions within this review, but it could be argued that this would benefit from being classified as a separate illness representation construct in mental health. Consideration needs to be made as to whether CYP's mental health illness perceptions have more emphasis on 'why' they have experienced this illness in comparison to experiencing a physical health condition and whether this alters the current model dimensions. This would fit with the understanding of different underlying mechanisms contributing to mental health conditions as compared to physical health conditions, with a clearer disease process, such as diabetes. Findings reported in three of the papers addressed the associations between illness perceptions and self-stigma. Corrigan and Watson (2002) describe stigma in two parts, public and self. Both with three aspects; stereotype

(negative belief about group/self), prejudice (agreement with belief and/or negative emotional reaction) and discrimination (behaviour in response to prejudice). This highlights the complexity of how stigma can be presented; as a belief, an attitude or a behaviour/outcome. Stigma has been researched extensively within mental health literature (Pescosolido, 2013). However, stigma in the context of illness perceptions has not been addressed as thoroughly. Chan and Mak (2016) argue self-stigma is a mediator between the SRM dimensions and outcomes, however the possibility of it being encapsulated in to the current dimensions or it being a dimension in its own right was not discussed. Within the papers reviewed self-stigma is seen as an attitude or an outcome, however, in an attempt to consider the possibility of further illness dimensions applicable to mental health in CYP stigma was explored as a possible illness representation.

The pervasiveness of stigma, in relation to mental health problems, endorsed in our society is well established (Angermeyer & Dietrich, 2005) and therefore stigma is likely to have a role in shaping an individuals' beliefs about their mental health problems. However, the role of stigma in the development and expression of illness perceptions has not yet been addressed (Lobban et al., 2004). The SRM, being originally designed for physical health conditions, may therefore not incorporate stigma-related illness perceptions in its current dimensions. Stigma was found to be associated with control and timeline, with individuals who perceived less personal control and mental health difficulties to be chronic having higher levels of self-stigma (Moses, 2010). Stigma was also associated to perceived consequences, emotional reaction and number of causes (Munson et al., 2009). With higher emotional responses to mental health, greater perceived consequences and endorsement of more causal factors associated with greater stigma experienced (Munson et al., 2009). Self-stigma was found to be negatively associated with coping and satisfaction with life, with less self-stigma linked with a greater use of coping strategies and greater satisfaction with life (Gaziel et al., 2015). There was a contradiction in terms of whether self-stigma was positively or negatively associated with illness coherence, with one study reporting participants who reported higher insight into their disorder had higher self-stigma and another reporting participants who had more coherent understanding of their illness were indifferent to stigma (Gaziel et al., 2015; Munson et al., 2009). These results suggest that reducing individuals' levels of stigma and/or empowering them to effectively cope with it, may reduce the perceived high consequences of individuals' mental health problems and increase satisfaction with life. Further research is needed to establish if improving understanding/insight into one's illness increases or reduces self-stigma. With the associations to other illness

representation dimensions and outcomes it is conceivable that stigma could be an illness representation to be incorporated in the SRM for mental health conditions. It could also be argued that stigma can be incorporated into the consequences dimension of the SRM, with the definition referring to the impact of the illness on social well-being of self and others. This may be appropriate; however, caution is needed to ensure that these findings, or further research suggesting additional dimensions, are not confined to existing dimensions in an attempt to apply the SRM to mental health conditions without adaptations. It would be beneficial to explore stigma related illness perceptions further in other mental health conditions, and in comparison to other more stigmatised physical health conditions such as HIV, to determine if this is a viable and predictive adaptation to the model.

Measurement of illness perceptions in CYP with mental health conditions

The IPQ-R has been used extensively to measure illness perceptions in physical health and has been validated within a wide range of health conditions but to date, has not been validated with CYP with mental health conditions. Only two studies in the current review utilised the full IPQ-R questionnaire. The findings by Munson et al. (2009) and Imran et al. (2015) provided evidence that the IPQ-R is an appropriate tool to measure illness perceptions in CYP with mental health conditions. The reliability coefficients, reported by Munson et al. (2009), were adequate-strong for the illness perception dimensions with the exception of the control dimension. Further, many of the inter-correlations among dimensions were consistent with previous research among adults with various health conditions (Cabassa et al. 2008; Moss-Morris et al. 2002). However, there are no norms currently available for the IPQ-R measure which makes interpretation of the scores reported difficult. Therefore, the IPQ-R appears to have face validity in this population but further testing with larger samples, and in comparison to other measures, is required to ensure construct validity and provide norms. By incorporating qualitative studies and studies that have utilised other measures in the current review, it has been possible to explore mental health illness perceptions that may not fit within the dimensions of the SRM and therefore are not recorded by the IPQ-R. The study findings related to stigma were discussed as a possible IP dimension, not addressed adequately by the current SRM dimensions. Therefore, it may be beneficial for stigma-related IPs to be incorporated into versions of the IPQ-R for CYP with mental health difficulties and to be considered and examined as another possible dimension in the SRM. Previous adaptations to the IPQ-R have been made to support its use in certain populations (Marcus et al., 2014) and therefore it is plausible amendments would be useful for different

mental health conditions. However, the application of one illness perception measure would benefit data synthesis and allow for comparison of findings, which would enable further investigation of the SRM.

Establish if the findings varied across mental health conditions

The second aim of the review was to establish if the findings varied across mental health conditions. Due to the limited number of studies and the wide variance in diagnoses within the studies, it was not possible to differentiate illness perceptions across mental health conditions. The SRM has been evidenced as applicable to a wide range of physical health conditions in both adults and CYP (Hagger & Orbell, 2003; Juergens et al., 2010; Law et al., 2014; Petrie & Weinman, 1997). It is also reported that the SRM is applicable to a range of mental health conditions within an adult population (Baines & Wittkowski, 2013). The results of this review provide preliminary evidence that the dimensions are applicable to a range of mental health conditions in CYP, however further research into specific conditions is required for a comparison of illness perceptions to be completed.

Limitations

The results of the review have provided preliminary evidence in determining the applicability of the SRM and defining the illness perceptions within this population. However, there are limitations within the studies sourced and therefore limitations in the conclusions that can be made from the review.

Literature/Study Limitations

The quality of the individual studies was examined as it is important to consider the methodological rigour of the studies when determining the reliability of the results. However, the quality rating was not used as an exclusion criterion, due to the limited research within the field and no other evidence at a higher standard available (NIHR, 2014).

The current review showed that the quality of the included papers was generally fair, with two papers being graded as poor. The quality was mainly limited due to biases in reporting of participant selection, small sample sizes and lack of consideration of potential confounding variables. The papers were also all cross-sectional which, as a result, provide weaker evidence than other cohort, RCT or longitudinal studies. The lack of studies exploring the causal direction of the relationship between variables means no definitive conclusions can be determined in

terms of whether illness perceptions are a risk factor for a worse prognosis or if greater illness severity and distress might lead to more negative illness perceptions. This is an area that needs further examination, with RCTs and longitudinal studies, to determine the direction of the relationship and ultimately which factors need to be addressed and intervened with to result in a change to outcomes.

In consideration of the study samples, all participants were engaged in mental health services. This may influence the illness perceptions reported, in comparison to those who are not in receipt of services, because for example they do who do not seek help or refuse treatment, and therefore may not be representative of all CYP who have a mental health condition. Munson et al. (2009) considered how the positive attitudes towards seeking support may have been a result of participants' current experiences and CYP not accessing services may hold different attitudes towards seeking support. To test this, further research would need to obtain the views of individuals who drop out of services or refuse treatment. Another issue for consideration is degree to which CYP illness perceptions are their own views and not those of their primary caregivers and this may be influenced depending on how and where measures of illness perception are completed.

Review Limitations

The review inclusion/exclusion criteria resulted in eight eligible studies. As the search terms and inclusion criteria were designed to be broad it can be assumed that this is an accurate reflection of the available literature in this area. This reveals the limited research that has been conducted in this field. The review was conducted within the recommended PRISMA guidelines for systematic reviews (Higgins & Green, 2011) in order to reduce the impact of biases. Part of this involved the process of including two independent raters from the initial search stages through to reading titles and abstracts, full texts, as well as quality assessment review. Furthermore, target papers found in a preliminary ad hoc search were used to ensure that the search terms encompassed these findings and their key words and a reference lists screened, to minimise the risk of not identifying possible relevant studies. However, there are several limitations that warrant caution in interpreting the findings.

The limited number of studies reduces the representativeness of the sample in regard to the illness perceptions of the wider population of CYP with mental health conditions and, therefore, the extent to which conclusions can be drawn about the applicability of the SRM. However, the results provide preliminary support for the SRM and the illness perceptions endorsed by this

population. The studies varied extensively with regards to heterogeneity of mental health presentations and severity of illness within the samples. This meant the second aim of the review, to establish if the findings vary across mental health conditions, could not be completed. In addition, across the studies, the research aims were diverse as were the methods of conceptualising and measuring illness perceptions and the outcomes of interest. Another limitation of the studies and the measures used is that there are no clinical norms or cut off scores. This poses a challenge in interpreting the scores reported and determining the clinical value of the scores.

The terms used to describe illness perceptions within the literature are varied. This poses a challenge when reviewing and summarising results and highlights a need for researchers to be more systematic in the definitions. The study samples also varied in ethnic and cultural backgrounds, which is valuable to establish cultural variance when a wider sample is available, however with a small sample may result in less clarity. Imran et al. (2015) discussed the differences with their results and that of Munson et al. (2009) who suggested cultural differences between Pakistan and America may account for these variances, however, with only two studies this conclusion cannot be definitive. The reviewed studies used associations to make links between illness beliefs and clinical outcomes, meaning causality cannot be determined. This has been reported as a limitation with the adult literature as well (Baines & Wittkowski, 2013). To determine the causal nature of such relationships, longitudinal and intervention studies are required to show the influence of interventions aimed at challenging negative illness perceptions and explore how this impacts upon clinical outcome. These designs will also allow exploration of how illness perceptions may change over time.

Implications

Research implications

This systematic literature review returned eight papers that were relevant which highlights the limited research that has been conducted exploring or analysing illness perceptions in CYP with mental health conditions. Further qualitative research is necessary to explore the breadth of CYP's mental health illness perceptions to establish if the SRM can encompass all the illness perceptions specific to mental health. Revisions to the model may be necessary but this is only possible with bottom up approach. In addition, better quality studies using the IPQ-R in larger samples with a specified mental health diagnoses are needed to validate the measure within this

population, with amendments if required. This needs to be completed so on-going research can routinely use the same measure, which will allow statistical analysis across samples and comparison across mental health conditions to rigorously test the model and build a wider understanding of illness perceptions within mental health.

Clinical implications

The ultimate goal of IP research is to determine whether understanding and examining IPs is useful in predicting certain outcomes and establishing how therapeutic intervention may be able to address unhelpful IPs in a beneficial way for the individual (Hale et al., 2007). Baines and Wittkowski (2013) reported that the reviewed literature regarding adult illness perceptions of mental health conditions demonstrated clear associations between illness perceptions and outcomes, such as readiness to change, treatment adherence, and reductions in symptoms and emotional distress. Within the current literature, a range of associations have also been found between CYP's illness perceptions and outcomes such as adherence, satisfaction with life, coping, self-esteem and internalising and externalising problems. Interventions aimed at targeting illness beliefs may be very important in helping individuals seek out support, engage with services, comply with interventions or treatments and result in a reduction in symptoms and emotional distress. Hale et al. (2007) proposed that the SRM can be used to tailor CBT interventions to adjust illness perceptions and improve outcomes. However, even as an initial stage, it would be beneficial to routinely ask about illness perceptions and consider how negative beliefs may be related to coping and health-related behaviours in formulation. With such promising therapeutic benefits and possible improvements in clinical outcomes, this is an area of research that cries out for further investigation.

Summary

The current systematic review is the first to date to assess studies which have explored illness perceptions CYP with a mental health condition. Eight papers were identified, and the findings indicate that the illness perception dimensions, outlined within the SRM, are largely endorsed by CYP experiencing a range of mental health problems. This provides further support that the SRM is applicable to mental health, consistent with the adult literature and that it is appropriate for CYP, corresponding to the literature exploring illness perceptions in young people with a physical health condition. The studies also provided evidence of associations between illness perceptions and clinical outcomes. However, conclusions are limited due to the number and

relative quality of identified studies. For further clarity on the applicability of the SRM and to ensure all illness perceptions are addressed by the model further researched is required. Due to the lack of studies, it was not possible to compare mental health conditions, therefore it would be beneficial for future studies to assess the application of the SRM to different mental health conditions and a further systematic review completed. The potential benefits to therapeutic intervention and outcomes, emphasises the need for more extensive research.

Conclusion

One in ten children and young people (CYP) aged 5–16, have a clinically significant mental health condition (Green, McGinnity, Meltzer, Ford, & Goodman, 2005). In addition to this, 50% of adults with a lifetime mental illness experienced symptoms by the age of 14 years (Kessler et al., 2005). In the UK mental health problems during childhood and adolescence in the UK result in increased costs of between £11,030 and £59,130 annually per child (Suhrccke, Pillas, & Selai, 2008). To reduce the level of burden on the NHS early intervention in childhood and adolescence is crucial and is a priority in National Institute for Health and Care Excellence (NICE) guidelines and standards (CG155, 2013; QS80, 2015).

This review establishes that Illness perceptions of CYP with mental health difficulties are linked with outcomes, with negative beliefs associated with poorer outcomes. The findings indicate that the SRM illness dimensions are applicable to CYP in a mental health setting and the conclusions highlight the importance of recognising illness perceptions as a potential risk factor for a worse prognosis. Therefore, illness perceptions of CYP are a key area for intervention, with the potential to be cost-effective and implemented easily if incorporated into current standard care. A stronger evidence base is necessary to determine the full applicability of the SRM to CYP with mental health conditions and to build upon the understanding of how illness perceptions impact on outcomes.

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MAIN RESEARCH PROJECT

The impact of discrepancies in illness perceptions,
between parent and child, in childhood unusual
experiences

First Supervisor:

Dr Suzanne Jolley, Senior Lecturer and Consultant Clinical Psychologist
Institute of Psychiatry, Psychology & Neuroscience

Second Supervisor:

Dr Juliana Onwumere, Lecturer and Clinical Psychologist
Institute of Psychiatry, Psychology & Neuroscience

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Abstract

Background

Unusual experiences (UEs) have increasingly been established as a predictor of 'at risk' mental state. This has led to the investigation of appropriate interventions to target vulnerability risk factors in children and young people (CYP) to prevent transition to a clinical condition. A risk factor that has been considered is illness perceptions, which have been shown to be predictive; with negative illness perceptions predicting poorer clinical outcomes. Negative perceptions from relatives have also been shown to have a significant negative effect, which has led to the consideration of discrepancies in illness perceptions between patient and carer. The relationship between expressed emotion of the carer and outcomes has been substantially examined and evidenced in psychosis. However, limited research has examined how illness perceptions and EE interact. Assessing the influence of discrepant IPs between parent and CYP and the impact of this on child outcomes is vital for the development of early interventions for CYP with an at-risk mental state. Examining if the relationship between IP discrepancies and outcomes is impacted upon by different familial emotional environments will help determine if family interventions need to be considered, as is currently recommended for adults.

Aims

This study set out to understand the role of discrepant illness perceptions between children and young people reporting UEs and their parents, and the impact of expressed emotion on this relationship, with a view to informing the development early interventions targeting CYP with an at-risk mental state.

The specific hypotheses for this project were:

- 1) A greater illness perception discrepancy will be associated with poorer outcomes, specifically, greater UE severity and greater emotional and behavioural problems
- 2) Discrepancies in illness perception will be related to EE, with a greater IP discrepancy in high EE dyads compared to low EE dyads.
- 3) The relationships between illness discrepancy and outcomes will be moderated by EE.

Methods

The current study employed baseline data from two separate randomised controlled trial (RCT) studies. The current study was an observational, cross-sectional design with the disparity between child and parent illness beliefs (Illness perception discrepancy score) as the independent measure, and key outcomes (child and parental rated emotional and behavioural problems and child-rated unusual experience severity) as the dependent variables, with expressed emotion as a potential moderator.

Results

The results provide further information in relation to the IPs endorsed by CYPs with mental health difficulties. Providing evidence of associations between negative IPs and poorer outcomes, with a greater IP discrepancy between parent and CYP associated with greater UE severity and greater emotional and behavioural problems (hypothesis 1) and evidence of greater IP discrepancies in high EE dyads compared to the low EE dyads (hypothesis 2). The findings indicate that EE does not moderate the relationship between IP discrepancy and the outcomes, however there does appear to be some form of relationship that requires further investigation (hypothesis 3).

Conclusion

The findings indicate that negative IPs and discrepancies in IPs between parent and CYP are indicative of poorer outcomes. High EE parents were also likely to have greater discrepancies between their IPs and their child's in comparison to low EE parents. Despite EE not moderating the effect of IP discrepancy on outcomes, there does appear to be some interaction. These findings indicate that interventions addressing and adapting IPs of both CYP and parents would improve patient outcomes. IPs are a factor that need to be considered within early interventions for CYP with an at-risk mental state, to strive to reduce the prevalence of mental health conditions in CYP that can persist into adulthood.

Introduction

Unusual Experiences

Psychotic-like, or unusual experiences (UEs), describe beliefs such as persecutory ideas or magical thinking and altered perceptions like hearing or seeing things that others cannot (Yung et al., 2009). These are common in the general population, particularly in childhood with between 25 and 50% of young people having experienced at least one UE (Laurens et al., 2007; Linscott & Van Os, 2013; Schultze-Lutter, Michel, Ruhrmann, & Schimmelmann, 2018). UEs have been associated with current and future risk of a range of mental health difficulties (Downs, Cullen, Barragan, & Laurens, 2013; Fisher et al., 2013; Kelleher et al., 2014; Kelleher et al., 2013), but for the majority UEs are transient and not indicative of later mental health problems. However, for a small minority of children and young people (CYP), approximately 6-14% of those experiencing UEs, these are persistent and distressing (Kelleher et al., 2013; Laurens et al., 2007) UEs are predictive of poorer outcomes for CYP when they are associated with distress and functional, emotional and behavioural difficulties (Laurens, Hobbs, Sunderland, Green, & Mould, 2012; van Os & Reininghaus, 2016). Studies indicate that whilst the likelihood of having UEs decreases with age, the likelihood of UEs being associated with distress and adverse functional impact increases (Kelleher et al., 2012; Kelleher et al., 2015; Pontillo, De Luca, Pucciarini, Vicari, & Armando, 2016). Persistence of these experiences in addition to limited protective and coping strategies increases the likelihood of developing psychosis and a range of other mental health problems (Asher et al., 2013). UEs have increasingly been established as a predictor of 'at risk' mental state (Tor et al., 2017). It has long been reported that around half of adults with a lifetime prevalence of mental illness have experienced symptoms by the age of 14 years (Kessler et al., 2005). Therefore, studies have aimed to understand the trajectory of mental health and psychosis and how interventions at different stages may reduce risk and prevalence (Schmidt et al., 2015). This has led to the investigation of appropriate interventions to target vulnerability risk factors in CYP to prevent transition to a clinical condition (Poulton et al., 2014). Current findings suggest that a broader, transdiagnostic form of support is may be more appropriate for CYP who display UEs rather than adult orientated CBT specifically for psychosis (Maddox et al., 2013; Stain et al., 2016; van Os & Guloksuz, 2017). National Institute for Health and Care Excellence (NICE) guidelines currently recommend intervention for CYP seeking help for UEs, using cognitive behavioural therapy (CBT) to address associated difficulties with mood and functioning (CG155, 2013, QS80, 2015). Further understanding of the factors that predict

levels of distress and limited coping strategies is crucial in the improvement of interventions for CYP with an at-risk mental state. To reduce the level of burden on mental health services from later presentations, early intervention in childhood and adolescence is considered crucial and is a priority in national guidelines and standards (National Institute of Health and Care Excellence, CG155, 2013; World Health Organisation, 2013).

Unusual Experiences and appraisal

The cognitive model of positive symptoms of psychosis specifies the cognitive, social and emotional processes hypothesized to contribute to the occurrence and persistence of symptoms (Garety, Bebbington, Fowler, Freeman, & Kuipers, 2007). The model proposes that the presence of psychotic experiences does not determine transition to psychosis alone, instead it hypothesized that specific cognitive and emotional factors contribute to the emergence of a clinical disorder, and, primarily, the appraisals made of both the primary perceptual experiences, and secondarily of the meaning of any changes the person notices in their mental wellbeing and functioning (Garety et al., 2007). Thus, it is the perception and appraisal of changes that causes the associated distress and disability (Chadwick & Birchwood, 1994; Morrison & Baker, 2000). If applying this model to CYP it would suggest that the impact of UEs on the young person, and potentially the development of an at-risk mental state, would be influenced by negative perceptions of the UEs. Although this model was initially established for an adult population early evidence suggests it is applicable for CYP (Ames et al., 2014; Bird, Waite, Rowsell, Fergusson, & Freeman, 2017)

The role of illness perceptions

Secondary or illness appraisals within cognitive models of psychosis and UEs can be clearly understood within a model of adjustment to a health threat, such as the Self-Regulation Model (SRM; Leventhal, Nerenz, & Steele, 1984). The SRM theorises that individuals have emotional and cognitive representations of the health threat which jointly influence the individuals' style of coping, their appraisal of how they are coping and their subsequent behaviour (Leventhal, Leventhal, & Cameron, 2001). The model predicts that illness perceptions (IPs) can be clustered into five core cognitive constructs: Identity (the label given to the illness and which symptoms are associated with it), timeline (how long the illness will continue), cause (what caused the illness), control (how well the illness can be personally controlled or controlled with treatment), and consequences (the effects of the illness on life) (Lobban, Barrowclough, & Jones, 2005). The SRM proposes that an individuals' IPs can adapt and change with new information and experiences and as a result alter their behaviours and outcomes (Petrie & Weinman, 1997). Illness perceptions have been investigated extensively in physical health across numerous conditions in both adults and CYP, and the SRM

constructs have been shown to be predictive, with negative IPs predicting poorer outcomes (for review see: Hagger & Orbell, 2003; Haller, Sanci, Sawyer, & Patton, 2008; Law, Tolgyesi, & Howard, 2014).

IPs have been explored less in mental health, however, similar findings have been established (Baines & Wittkowski, 2013; Fortune, Barrowclough, & Lobban, 2004; Lobban, Barrowclough, & Jones, 2006; Juliana Onwumere et al., 2008; Watson et al., 2006). As the systematic literature review, earlier in this volume, demonstrated, there is very limited research examining IPs in CYP with mental health difficulties. However, the available literature indicates that negative IPs have a significant influence on coping, quality of life and treatment outcomes for CYP experiencing mental health difficulties (Gaziel et al., 2015; Imran, Azeem, Chaudhry, & Butt, 2015; Moses, 2010, 2015; Munson, Floersch, & Townsend, 2009, 2010).

Given these findings, consideration has been given to IPs as targets of cognitive interventions to promote more adaptive appraisals, coping strategies and, in turn, enhance clinical outcomes (Petrie, Cameron, Ellis, Buick, & Weinman, 2002; Petrie, Jago, & Devcich, 2007). It has been proposed that interventions can change illness representations by targeting cognitions or by targeting behaviours, with psychoeducation or with adaptive coping strategies (McAndrew et al., 2008). Studies in this area are limited, however preliminary results are promising: Improvements in recovery and levels of distress have been shown in both adults following a myocardial infarction and those with Lupus (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009a, 2009b; D. Goodman, Morrissey, Graham, & Bossingham, 2005; K, Cameron, Ellis, Buick, & Weinman, 2002; Petrie et al., 2002). These findings provide preliminary support for the clinical benefits of incorporating IPs into interventions and such interventions appear feasible and applicable not only to physical illnesses but also to mental illnesses (Petrie, Broadbent, & Kydd, 2008).

Discrepant illness perceptions

The SRM emphasises the role of significant others in shaping the beliefs that people have about their own health problems and the coping strategies that they use (Leventhal et al., 1984). IPs held by carers and family can affect the individuals' own IPs and subsequently their health-related behaviour and outcomes. Negative perceptions from relatives have been shown to have a significant negative effect on patients' well-being, functioning and coping in both adults and CYP (Heijmans, Ridder, & Bensing, 1999; João Figueiras & Weinman, 2003; Morgan, Villiers-Tuthill, Barker, & McGee, 2014; Salewski, 2003; Thompson & Pitts, 1992). Despite an individuals' IPs being influenced by those around them, it is unlikely that IPs will

be identical due to different environmental factors, discrete experiences and the differing appraisals each individual will make in forming their IPs (Petrie & Weinman, 1997). Therefore, it is worth considering if differences in IPs between the person with the condition and those who support and care for them can also impact emotional responses, coping and outcomes. The impact of dissimilar or discrepant health beliefs of family members was considered early on in the development of the SRM, with Leventhal suggesting congruence could increase the family's ability to cope and incongruence could result in a reduction in family solidarity (Leventhal, Safer, & Panagis, 1983). It is feasible that if two people (a dyad) have congruent IPs that the patient may feel understood and supported, but if they are incongruent or discrepant in IPs, this may cause the patient to feel conflicted, frustrated, and as a consequence, experience more distress.

[Evidence for the clinical impact of illness discrepancies](#)

IP discrepancy research is in its infancy, however some evidence has been established. In the context of chronic fatigue syndrome, Addison's disease and head and neck cancer, adult patients and their spouses were found to report significantly different IPs (Heijmans et al., 1999; Richardson, Morton, & Broadbent, 2015). Spouses/Carers perceived the illness as more of a threat and both negative IPs and IPs discrepancies were associated with less adaptive coping, poorer well-being and worse perceived quality of life (Heijmans et al., 1999; Richardson et al., 2015). However, in myocardial infarction and eating disorders, dyads agreeing on the illness as negative had poorer functioning and worse recovery than that of similarly positive dyads and discrepant dyads, who had similar outcomes (João Figueiras & Weinman, 2003; Quiles Marcos, Weinman, Terol Cantero, & Beléndez Vázquez, 2009). It is plausible that the impact of discrepancies on CYP outcomes will be greater than in adults, due to the nature of the hierarchical nature of the parent-child relationship, cognitive and emotional development vulnerabilities and the child being more dependent (Sigel, McGillicuddy-DeLisi, & Goodnow, 2014). Findings suggest that significant discrepancies in IPs were found between CYP and their parents, with parents perceiving the illness as more negative and believing more strongly in treatment, in both diabetes and skin disease (Gaston, Cottrell, & Fullen, 2012; Salewski, 2003). Gaston et al. (2012) found an association between IP discrepancies and clinical outcomes, in relation to diabetes, with families reporting similar IPs associated with better CYP well-being, whereas, Salewski (2003) found a discrepancy between family members' IPs, in relation to chronic skin disease, but they had little impact on CYP's wellbeing and distress. However, perceived family cohesion was a good predictor of adolescents' wellbeing and strain. Heyduck, Bengel, Farin-Glattacker, and Glattacker (2015) qualitatively examined IPs of CYP with asthma and their parents, finding congruence

in the CYP-parent dyads in relation to most of the themes established, but discrepancies regarding the impact on the CYP's life. These mixed results could indicate that the effect of a discrepancy in IPs is moderated by factors such as the characteristics of the illness, and therefore may not have the same impact across different physical and mental health conditions (Heijmans et al., 1999). However, for this hypothesis to be tested, further investigation of the possible moderating factors is needed, in relation to different physical and mental health conditions.

Cognitive model of caregiving

IP discrepancies have been studied in psychosis in relation to the cognitive model of caregiving (Kuipers, Onwumere, & Bebbington, 2010), which outlines how carers' appraisals of psychosis influence outcomes for both the carer and the adult with psychosis. The model proposes that the initial relationship between patients and carers, typically family members, will result in divergent outcomes. The model suggests that the initial relationship will influence how the carer appraises the problem and the relative. This will influence how they will react and their behaviour, both towards their relative and their ability to self-regulate, which will in turn influence their own wellbeing, and, through their response to the relative, their relative's wellbeing (Kuipers et al., 2010). This model is grounded on the same theoretical underpinnings as the SRM, and negative IPs of caregivers are closely linked with emotional and behavioural reactions. For example, carers' appraisals of personal control can result in different emotional responses: Anger linked to beliefs that the individual can control their behaviour, pity linked to beliefs that the individual is unable to control their behaviour, and guilt linked to beliefs about their personal responsibility (Barrowclough, Johnston, & Tarrier, 1994; Lobban, Barrowclough, & Jones, 2003).

Expressed emotion

The term 'expressed emotion' (EE) describes the way in which a carer or parent speaks about, and behaves towards, a family member with an illness (Barrowclough & Hooley, 2003). The cognitive model of caregiving describes three types of relationship. Each relationship is characterised by particular communication styles, or expressed emotion, and predicts different appraisals, behaviours and outcomes according to the relationship type (Kuipers et al., 2010). The different types of relationship are: positive (low EE/warmth), emotionally over-involved and critical/hostile (both considered to be high EE). EE can be measured with a semi-structured interview, using either the Camberwell Family Interview (CFI; Vaughn & Leff, 1976) or the Five-Minute Speech Sample (FMSS; Magaña et al., 1986). The CFI includes scales on criticism, hostility, emotional over-involvement, warmth and positive comments.

The FMSS is a briefer interview method which includes scales of criticism and emotional over-involvement. These measures result in a rating of either high or low EE.

The clinical impact of EE

The relationship between EE and outcomes has been substantially examined and evidenced in psychosis, with high EE associated with a two-fold increase in rates of relapse in schizophrenia compared to a low EE household (for review see: Butzlaff & Hooley, 1998). These studies indicate that the quality of the relationship between people with psychosis and their relatives is an important predictor in determining patient outcomes (Butzlaff & Hooley, 1998). The significance of these results has led to the development of family interventions that aim to reduce high levels of EE (Claxton, Onwumere, & Fornells-Ambrojo, 2017). Family intervention has been extensively shown to be successful in reducing the number of relapse events and hospitalisations, improving medication adherence, general social impairment and reducing levels of expressed emotion within the family (Claxton et al., 2017; Pharoah, Mari, Rathbone, & Wong, 2010). Family interventions are recommended first line psychological treatments for patients with psychosis in many areas across the globe including the United Kingdom (UK), Canada, USA and Australia in the National Institute of Health and Care Excellence standards (Castle et al., 2017; QS80, 2015; Norman, Lecomte, Addington, & Anderson, 2017). In recognition of the evidence in psychosis, the utility of measuring EE has also been examined in other mental and physical health problems, with EE found to be associated with a range of patient outcomes (Bader, Barry, & Hann, 2015; Safavi, Berry, & Wearden, 2017; Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). Several studies have also evaluated the impact of EE in CYP. Studies examining parental EE in chronic medical conditions showed high EE to be associated with poorer metabolic control in school age children with diabetes (Liakopoulou et al., 2001) and more frequent and severe asthma attacks of children with asthma (Schöbinger, Florin, Zimmer, Lindemann, & Winter, 1992). This relationship has also been explored in relation to CYP with mental health conditions, with high EE was associated with: relapse and re-hospitalization of children with depression (Asarnow, Goldstein, Tompson, & Guthrie, 1993; Silk et al., 2009), poorer outcomes and relapse in young people with schizophrenia (King, 2000; King & Dixon, 1999), increased risk of psychiatric diagnosis (Peris & Miklowitz, 2015; Stubbe, Zahner, Goldstein, & Leckman, 1993) and criticism related to increased child problems (Ammerman & Brown, 2018; Musser, Karalunas, Dieckmann, Peris, & Nigg, 2016).

Reviews of prospective and retrospective studies have shown that parental EE is a risk factor for long-term outcomes in child and adolescent psychopathology, including the development, course and outcomes of child mental health problems (Wearden et al., 2000).

Peris and Baker (2000) found that high EE predicted children's problem behaviour four years later, suggesting a causative rather than consequential role in the development of child problems. However, it is possible that EE is a maintaining or exacerbating factor rather than a causal one (Bolton et al., 2003). Goldberg-Arnold, Fristad, and Gavazzi (1999) conceptualised high EE as both a stressor for the child with a mental health problem, and also as an interactional variable between parent and child. They suggest that the child's symptomatic behaviour acts as a stressor for parents, which exacerbates EE, and in turn leads to more critical, hostile or over-involved interactions. Therefore, further research is needed to understand the relationship between EE and outcomes in CYP.

Limited research has examined how illness perceptions and EE interact, with the exception of Lobban et al. (2006) and Kuipers et al. (2007). Lobban et al. (2006) explored IP discrepancies in patients with a diagnosis of schizophrenia and their relatives in relation to EE. The results showed a greater IP discrepancy between high EE dyads compared to low EE dyads and that this discrepancy was associated with poorer outcomes. Kuipers et al. (2007) assimilated Lobban et al.'s (2006) method for use with adults with schizophrenia who had experienced a relapse. The findings demonstrated that carers were more negative than patients about the timeline and consequences of the illness and discrepant IPs were associated with increased anxiety, depression and reduced self-esteem in patients. However, Kuipers et al. (2007) did not find an association between IPs and EE. The findings indicate that discrepant beliefs about psychosis, between patient and carer, may cause increased distress for both the carer and patient and influence clinical outcomes. However, with only two studies it is not possible to draw firm conclusions on the moderating effect of EE.

Current Study

Assessing the influence of discrepant IPs between parent and CYP and the impact of this on child outcomes is vital for the development of interventions for CYP, in particular early interventions for CYP experiencing UEs. Examining if the relationship between IP discrepancies and outcomes is impacted upon by different familial emotional environments will help determine if family interventions need to be considered, as recommended for adults. Understanding these factors may inform the development of specifically designed interventions to improve IPs and promote concordance of IPs in families. This work aims to support the continued development of our standards of care and ensures all risk factors are examined at this critical stage for CYP with an at-risk mental state.

Therefore, the current study set out to understand the role of discrepant IPs between CYP with UEs and their parents, with a view to informing early interventions, based on the

findings of the current adult literature. Investigating this association earlier may enable detection of those individuals at risk of future mental health difficulties. The study aimed to expand our knowledge of the IPs of CYP experiencing mental health difficulties and their impact on outcomes, specifically UE severity and emotional and behavioural problems, whilst considering the impact of EE on this relationship. No study, to date, has addressed IPs in CYP in relation to UEs.

Hypotheses

The specific hypotheses for this project were:

- 1) A greater illness perception discrepancy will be associated with poorer outcomes, specifically, greater UE severity and greater emotional and behavioural problems
- 2) Discrepancies in illness perception will be related to EE, with a greater IP discrepancy in high EE dyads compared to low EE dyads.
- 3) The relationships between illness discrepancy and outcomes will be moderated by EE.

Method

Research Setting

The current study employed baseline data from two separate randomised controlled trial (RCT) studies, both investigating UEs and therapy outcomes in young people; the Coping with Unusual ExperienceS for Children (CUES) study (ISRCTN13766770), and the Coping with Unusual ExperienceS for 12 to 18-year olds (CUES+) study (ISRCTN21802136). Both studies were based in community Child and Adolescent Mental Health Services (CAMHS) within the South London and Maudsley National Health Service Foundation Trust (SLaM). CUES and CUES+ were both awarded ethical approval by London Hampstead Research Ethics Committee (Ref: 11/LO/0023 and 14/LO/1970). Research approval was granted by the CAMHS Clinical Academic Group and the local NHS Trust (reference R&D2011/028; R&D2015/003).

Design

The current study was an observational, cross-sectional design with the disparity between child and parent illness beliefs (Illness perception discrepancy score) as the independent measure, and key outcomes (child and parental rated emotional/behavioural problems and child-rated unusual experience severity) as the dependent variables. The current study was concerned only with data obtained at the baseline phase of the longitudinal CUES and CUES+ projects (described below).

The method for the proposed study was based on the methodological designs of Lobban and colleagues (2006), and Kuipers and colleagues (2007) who examined the relationship

between mean discrepancy scores on the IPQ and high and low EE relatives of adult patients with schizophrenia and psychosis and the impact of these on clinical outcomes. This study examined this relationship in a younger population of patients referred to mental health services with respect to unusual experiences.

Participants

Current Study Sample

Participants aged between 8-18 years old who had been referred to CAMHS services due to emotional, behavioural and mental health difficulties and had taken part in the CUES Pilot or CUES+ studies formed the participant pool for the current study. To be included in the current study sample, participants had to have an IP discrepancy score (i.e. both the young person and the parent had completed the measure of illness perceptions) and at least one clinical outcome score. The exclusion of participants missing either of these measures was necessary due to the primary focus being discrepancies in illness perceptions between CYP and parent. This resulted in a total of 156 CYP-parent dyads (Figure 3).

CUES and CUES+

The CUES and CUES+ projects were RCTs to assess the effectiveness of an adapted Cognitive Behavioural Therapy (CBT) programme in reducing distress in CYP who report unusual experiences and emotional problems. The CUES study recruited 110 participants and the CUES+ study 122 in total.

CUES pilot recruitment

CYP aged between 8-14 years at the time of referral to CAMHS Tier 2 services (providing support for emotional and behavioural difficulties) were invited to take part in the study, whilst on the waiting list for CAMHS treatment as standard. For inclusion, parents were required to have sufficient English language skills to complete the measures (with audio support or appropriate researcher assistance) and provide informed consent and the CYP provide informed assent. Participants also needed to live locally and in stable living arrangements so as to complete the intervention. All consenting CYP completed baseline assessments, therefore not all participants from the CUES study had unusual experiences.

CUES+ recruitment

The CUES+ project involved older children, aged 12- 18 years referred to CAMHS 'tier 3' South East London services. CYP who reported current unusual experiences, either with self-rated distress or a score within the clinical range on the emotional symptom subscale of the Strengths & Difficulties Questionnaire (SDQ; Goodman et al., 2000) were eligible for inclusion. In conjunction with sufficient English language skills to be able to complete the measures and therapy, availability for the duration of the intervention. CYPs were not eligible

if they had a previously identified learning disability (IQ below 70), a known neurological condition with the unusual experiences identified as a secondary phenomenon or the unusual experiences solely due to substance misuse. Those that reported unusual experiences (at the routine CAMHS screening) were given information sheets and consent forms, with the parents informed as appropriate. The consenting procedure for participants over 16 years was to initially obtain CYP consent and, following the CYP's agreement for parental participation, parent consent. Participants under 16 years old required parent consent and child assent. The baseline assessments were completed following consent, with randomisation for CUES+ intervention completed after assessment.

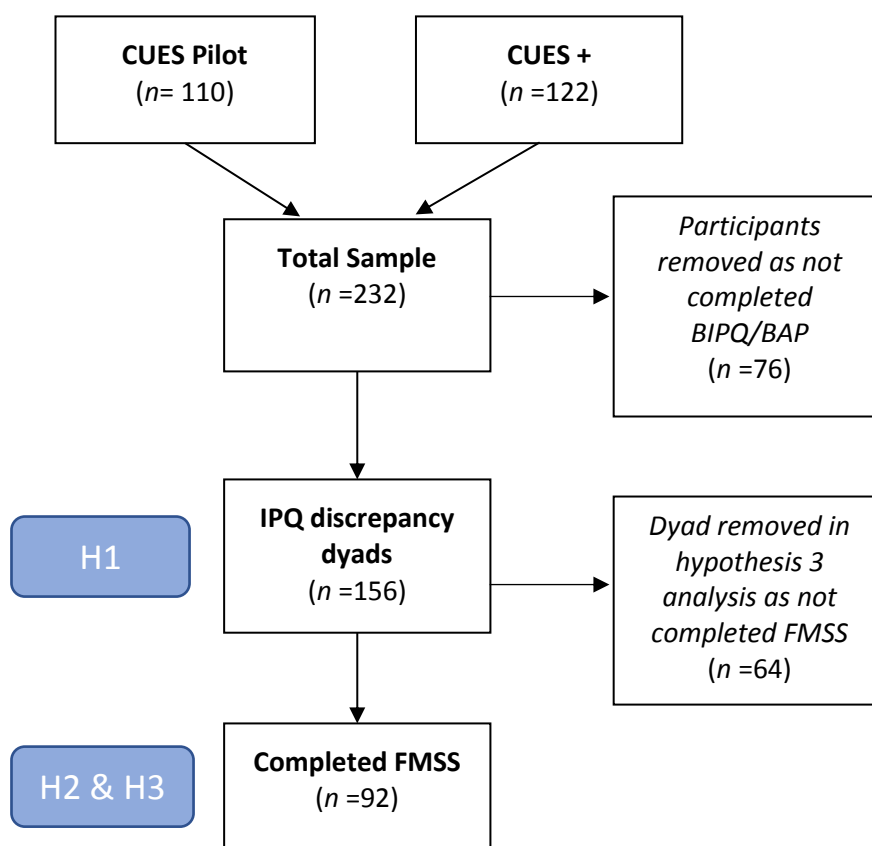


Figure 3. CONSORT diagram of study inclusion

Measures

Demographic information

Demographic data was collected via questionnaire by the parent as part of the baseline assessment battery. Age, gender and ethnicity of both the CYP and the parent was collected.

Illness perceptions discrepancy score

Discrepancy scores were calculated by subtracting parental total appraisal scores from child appraisal scores across seven items drawn from the Brief Illness Perception Questionnaire (B-IPQ; Broadbent, Petrie, Main, & Weinman, 2006) assessing cognitive and emotional illness representations. The B-IPQ has been shown to have good test-retest reliability and concurrent validity with the longer IPQ measure (Broadbent et al., 2006). It has been previously used to assess the appraisals of carers of people with psychosis (Berry, Barrowclough, & Wearden, 2009; Tomlinson, Onwumere, & Kuipers, 2014). The B-IPQ was adapted for parents so the word “illness” was replaced by “child’s problems”.

For young people, B-IPQ items were incorporated into a longer ‘Beliefs About Problems’ scale (Bradley, 2013) (Appendix 1). The questionnaire asks the CYP to rate the questions based on their current main problem or the reason they were referred. Both measures include seven items rated on 11-point (0-10) Likert scales that assess cognitive illness representations (Consequences, Timeline, Personal Control, Treatment Control, Coherence) and emotional representation. The individual item scores are calculated into a total score (with the coherence and control items reverse scored). The total score reflects the degree to which the individual perceives their problem/their child’s problem to be threatening (Broadbent et al., 2006). Higher scores indicate a more threatening perception of the illness with a Cronbach's α of 0.73. Taber (2017) suggests that an α in the range of 0.70- 0.80 represents good reliability. To calculate a discrepancy between the dyad, the total from the seven corresponding items on the BIPQ was then deducted from the BAP total and the difference used as the discrepancy score. This created a continuous variable that described the direction of difference. The greater the positive score, the higher the CYP scored compared with their parent. The more negative the score, the greater the parents scored compared with the CYP. A positive score indicates that the CYP perceived their mental illness to be more threatening (i.e. the child was more pessimistic) than the parent. A negative score indicates that the parent perceived their child’s mental health condition to be more threatening (i.e. the parent was more pessimistic) than the CYP.

Parental Expressed Emotion (EE)

EE was measured using the Five-Minute Speech Sample (FMSS; Magaña et al., 1986). This method requires the parent to speak about their child for five minutes, uninterrupted, and the taped interview can then be reliably rated to classify parents as high or low EE on the basis of criticism or emotional over-involvement (EOI). Parents were rated as ‘critical’ if they made a negative opening remark, if they provided evidence of a negative relationship with

their child, or if they made one or more criticisms in relation to the child during the course of the speech sample. EOI was rated on evidence of self-sacrifice or over-protectiveness, emotional display, excessive praise, preoccupation with the past or statement of attitude. If parents were rated as either critical, EOI, or both they were classified as high EE. Therefore, parents could be classified into one of four subcategories; neither critical nor EOI, critical, EOI or both critical & EOI. These subcategories were used for descriptive purposes and only high/low categorisation used for analysis. The speech samples were transcribed and coded by the author, as primary coder. The primary coder was trained by the supervisor (JO), an experienced trainer and rater of EE. The trainer independently rated a subsample of 13 speech samples (20%), to confirm adequate inter-rater reliability. Inter-rater agreement on individual subscales was also examined. Agreement was 100% on overall EE classification. The FMSS was chosen as the measure of EE as it is widely used and despite the method being less sensitive than the gold standard, CFI, it is more time efficient as part of a larger assessment battery (Hooley & Parker, 2006).

Outcome Measures

Unusual Experiences (UEs)

CYP-rated severity of UEs was evaluated using the Unusual Experiences Questionnaire (UEQ; Laurens et al., 2007) which consists of nine items rated on a three-point scale of conviction (0 = Not True, 1 = Somewhat True, 2 = Certainly True) (Appendix 2). The measure includes five items adapted from the Diagnostic Interview Schedule for Children (Costello, Edelbrock, Kalas, Kessler, & Klaric, 1982) and four assessing a wider range of UEs. The items assess the occurrence of hallucinatory experiences (e.g. "Have you ever heard voices other people could not hear?") and unusual ideas (e.g. "Have you ever felt you were under the control of some special power?"). The UE items that were endorsed by the CYP as either 'somewhat' or 'certainly true' were followed up with questions relating to frequency, distress and functional impact of the UE over the preceding two-week period. These were rated on a four-point scale ranging from 0 to 3 with higher scores indicating greater levels of frequency, distress and impact. Totalling the scores for those items gives an overall measure of severity of UEs with distress or adverse impact, with scores ranging from 0 to 99, greater severity indicated by higher scores. The endorsement items of the UEQ have been shown to have good internal consistency ($\alpha = 0.82$) and satisfactory construct validity as well as satisfactory agreement with clinical interview (Laurens et al., 2007).

Emotional and Behavioural Problems (CYP rated and parent rated)

The Strengths & Difficulties Questionnaire (SDQ; Goodman, Ford, Simmons, Gatward, & Meltzer, 2000) is a screening tool that measures behavioural and emotional difficulties in

young people aged between 3 and 16 years of age (Appendix 3) with both parent and self-report measures available. The measure consists of 25 items describing positive and negative attributes and can be divided into five subscales; emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviours (five items in each). The items are rated on a three-point scale ranging from 0 = not true, 1 = somewhat true, 2 = certainly true, giving a subscale score range of 0-10. A total difficulties score can be calculated from summing all the subscales (except the prosocial behaviour subscale) to give a score ranging from 0 to 40. The SDQ has been reported to be both valid and reliable (Goodman, 2001) and suitable for use with clinical samples (Goodman, Ford, Simmons, Gatward, & Meltzer, 2003). The measure is routinely used in mental health services and recent studies have indicated it is suitable for young people up to the age of 19 years (Van Roy, Veenstra, & Clench-Aas, 2008). Mean total difficulties scores reported in the normal population were 10.3 (SD=5.2) for CYP aged 5-15 years and 8.4 (SD=5.8) for parents (Meltzer, Gatward, Goodman, & Ford, 2000). Both a parent-report and self-report version was used in the current research.

Missing Data

The IP measure was introduced to the CUES pilot battery once recruitment had started resulting in reduced numbers completing it within the overall study sample and within CUES+ some CYP were not accompanied by their parents and therefore parental data was not available. There was also a proportion of parents that did not complete the FMSS accounting for the reduction in sample size for the third hypothesis. Missing data was prorated if two or fewer items were missing on any measure, and otherwise considered to be missing. Cases with missing data were excluded from relevant analyses and the *n* for each analysis reported. There was missing data for the UEQ severity score (*n*=1), parent-reported SDQ score (*n*=10) and EE classification (*n*=64).

The study sample was compared to those excluded because of missing data on demographic variables (age, gender, ethnicity) and the study variables (UEQ severity and SDQ score rated by parent and child). For hypotheses one and two, there were no differences in age and gender, but the study sample were less likely to be from a BME group (Chi-squared =7.38, *df*=1, *p*=0.007) and scored marginally higher on all study variables, but this did not reach statistical significance in any case (*t* values all <1.7, *p* values all >0.1). For hypothesis 3 (dyads who had not completed the FMSS) were not significantly different on study variables (*t* values all < 1.6, *p* values all > 0.1) but were significantly different on age, *t*(155)=-2.531, *p* =.01. However, the difference in years was not great (study sample mean = 13.01 (SD 2.34); missing mean 13.99 (SD 2.43)).

Power Considerations

Lobban and colleagues (2006) recruited a total of 49 dyads and found an effect size of approximately 0.6 between EE and IP discrepancy. Using this information to determine the sample size for this study, with power of 80% and alpha of 0.05, 84 participants are required to detect an effect size of 0.3 or larger, calculated using G*Power 3 (Faul, Erdfelder, Buchner, & Lang, 2009). To adjust for multiple testing, using an alpha of 0.01, 125 dyads were needed. For hypothesis one and two, a total of 156 participants had available data, however for hypothesis three only 92 participants had completed the FMSS. This number is still appropriate to detect an effect size of 0.3 or larger, but adjusted analyses should be treated with caution as they may be underpowered.

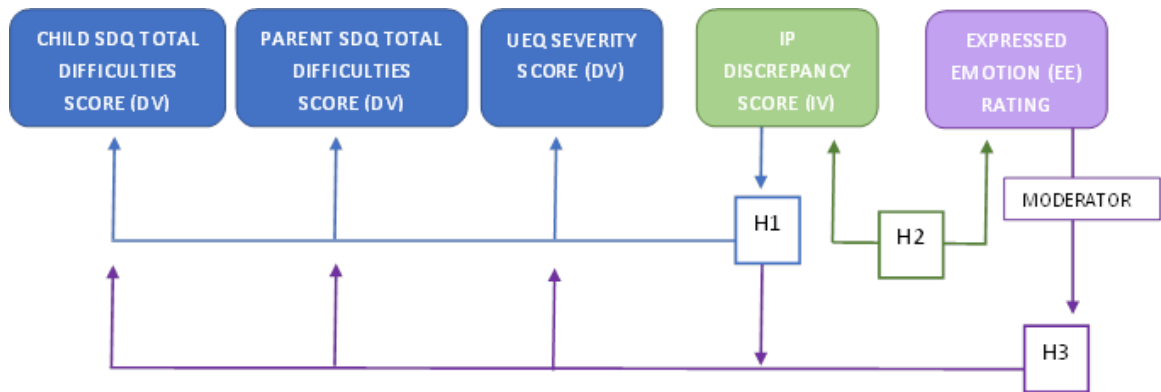
Planned Analysis

All statistical analyses were carried out using IBM SPSS Statistics (version 24, 2016). Initially the demographics and clinical characterisation of the sample were described. Variables of interest were examined for associations with demographic variables. Descriptive analysis of the IP items was also completed. Within the analysis both the direction and magnitude of the IP discrepancy were explored.

The associations between IP discrepancy scores and outcomes (CYP-rated UEQ severity score, CYP-rated SDQ total difficulties score and parent-rated SDQ total difficulties score) (hypothesis one) were examined using correlational analyses, followed by linear regression to establish the amount of variance in outcomes accounted for by IP discrepancy. The association between IP discrepancy score and EE status (hypothesis two) was examined using a t-test. The associations between EE and outcomes were examined using linear regression and the associations between IP discrepancy scores and outcomes with EE as a moderator (hypothesis three) were examined using correlational analyses and multiple regression. All tests were two-tailed.

The distribution of data was examined by visually inspecting histograms for skewness and kurtosis. Q-Q plots were visually inspected to determine normality of the data and the variables all appeared to be within the normal distribution, apart from the UEQ which was slightly positively skewed (Field, 2013). Statistical testing confirmed this with all residuals being normally distributed, as assessed by Shapiro-Wilk's test ($p > .05$), except for UEQ severity ($p = .013$ for hypothesis 1, $p = .007$ for hypothesis 2). A natural log transformation was attempted to compensate for this, as was using only the endorsement ratings of the UEQ (range 0-18), but the positive skew remained despite this. Correlational analyses of the

UEQ were repeated using a non-parametric Spearman test and r values reported. Results of regression analyses for the UEQ should be treated with caution.



SDQ = Strengths and Difficulties Questionnaire, UEQ = Unusual Experiences Questionnaire, IP = Illness Perceptions, DV= Dependent variable, IV = Independent variable. H = hypothesis.

Figure 4. Study Hypotheses in relation to variables of interest.

Results

Demographic characteristics of the sample

A total of 156 dyads of CYP and parents were included in the current study, 42% ($n=65$) from the CUES pilot and 58% ($n=91$) from the CUES+ study. The combined demographic data, for both CYP and parents is shown in Table 3. The majority of the CYP were female (60%) with a mean age of 13.4 years ($SD=2.42$ years), and a range of 8-17 years. The main carer completing the baseline data was most commonly the mother ($n=131$), but reports were also obtained from fathers, grandparents, step parents and legal guardians (Table 3). The mean age of the caregiver was 43.2 years ($SD=8.02$ years) with a range from 26-66 years. For ease, the main care provider group will be referred to as ‘parent’ throughout the rest of the study.

Table 3. Demographic information for study sample

	<i>N</i>	Percentage
CYP	156	
Female	94	60.3
Male	62	39.7
Ethnicity		
Non -BME	87	55.8
BME	69	44.2
Parent/Carer		
Relationship to CYP	146 [†]	
Mother	131	89.7
Father	8	5.5
Grandparent	3	2.1
Legal Guardian	3	2.1
Step Mother	1	0.7
Ethnicity	134 ^{† †}	
Non-BME	78	58.2
BME	56	41.8

BME = Black and Minority Ethnic, [†] missing data, not reported (*n*=10) ^{† †} missing data, not reported (*n*=22)

Pearson's *R* correlations (for the continuous variable of CYP age) and biserial correlations (for the binary variables of CYP gender and CYP ethnicity) were conducted to assess the associations between the variables of interest; IP discrepancy score, EE and outcomes (UEQ severity, CYP-rated SDQ total difficulties score, parent-rated SDQ total difficulties score) and demographic variables (age, gender and ethnicity). Pearson's *R* correlations demonstrated a significant association between age and IP discrepancy score, EE, UEQ severity and CYP-rated SDQ score but not parent-rated SDQ score (Table 4). There was also a significant correlation between gender and IP discrepancy, UEQ severity and CYP SDQ score but not a significant association with EE or parent-rated SDQ score. Ethnicity was not correlated with any of the variables of interest (*r*-values all < -0.4, *p* values all > .09). Due to these associations, analyses were repeated controlling for both gender and age.

Table 4. Relationship with variables of interest and demographic variables using Pearson's *R* correlations

	UEQ Severity (<i>n</i> =155)	CYP-rated SDQ (<i>n</i> =156)	Parent-rated SDQ (<i>n</i> =146)	EE (<i>n</i> =92)	IP Discrepancy Score (<i>n</i> =156)
Age	.21**	.22**	-.03	-.31**	.25**
Gender	.16*	.29**	.05	-.13	.29**
Ethnicity	-0.1	-0.14	.00	.09	-.04

CYP= children and young people, UEQ= Unusual Experiences Questionnaire, SDQ = Strengths and Difficulties Questionnaire, EE = expressed emotion, IP= illness perceptions. **p* < 0.05; ** *p* < 0.01. two tailed.

Clinical characteristics of the sample

Illness Perceptions

The mean scores for the IP items are reported for both parent and CYP groups in Table 6. Independent samples t tests were calculated to examine the mean difference between CYP and parent mean scores for each corresponding item and the total (Table 6).

Perception of timeline was the only item where the mean parent score was not significantly different to the CYP's mean score. The mean parent score was significantly more positive regarding treatment control and coherence and significantly more negative in relation to consequences, personal control, concern and emotional representation. Despite the items being significantly different, the overall IP items mean score indicates the parent and CYP group had similar scores.

Parent and CYP total IP item scores were tested for associations with the outcomes (UEQ severity, CYP-reported SDQ total difficulties score and parent-reported SDQ total difficulties score) using Pearson's R correlations. The results are shown in Table 5.

Table 5. Pearson's R correlations between CYP and Parent IP item total score and outcomes

	UEQ Severity score		CYP-rated SDQ score		Parent-rated SDQ score	
	<i>n</i>	<i>R</i>	<i>n</i>	<i>r</i>	<i>n</i>	<i>R</i>
CYP IP item total	151	.31**	152	.42**	142	.20*
Parent IP item total	150	.05	151	.16*	141	.27**

CYP= children and young people, UEQ= Unusual Experiences Questionnaire, SDQ = Strengths and Difficulties Questionnaire, EE = expressed emotion, IP= illness perceptions. * $p < 0.05$; ** $p < 0.01$. 2 tailed.

Illness Perception Discrepancy

The mean and range of IP discrepancy score between parent and CYP dyad is reported in Table 8. This indicates, on average, the parent was marginally more negative than their child. A total of 47 dyads (30%) had a discrepancy score over 1 standard deviation from the mean. 23 dyads with a discrepancy over 13 (child more negative) and 24 dyads with a discrepancy below -14 (parent more negative).

Table 6. Mean illness perception item scores and independent samples t-tests of mean difference between children/young people and their parents.

SRM Dimension	IP items	CYP			PARENT			GROUP COMPARISON				
		N	Mean	SD	N	Mean	SD	IP group mean discrepancy ¹	N	Std. Error Difference	t	CI (95%)
	0= positive perception 10= negative perception											
Consequence	1. How much does it affect your/your child's life?	156	6.91	2.79	156	7.90	1.71	-.99	156	.26	-3.80**	-1.51, -.47
Timeline	2. How long do you think it will continue?	155	6.55	2.82	154	6.52	2.30	-.01	153	.29	.10	-.55, .61
Personal Control	3. How much control do you feel you have/your child has over it? [†]	154	5.69	3.14	154	6.53	2.42	-.82	152	.32	-2.63**	-1.47, -.21
Treatment Control	4. How much do you think getting help can help with it? [†]	154	5.27	3.03	155	1.80	1.90	3.45	153	.29	12.07**	2.90, 4.04
Concern	5. How worried are you about it?	155	6.52	3.12	156	9.07	1.56	-2.55	155	.28	-9.13**	-3.10, -2.00
Coherence	6. How well do you feel you understand it? [†]	153	5.14	3.09	156	3.95	2.72	1.14	153	.33	3.60**	.54, 1.84
Emotional Representation	7. How much does it affect how you feel?	154	7.42	2.78	153	8.33	1.88	-.86	151	.27	-3.38**	-1.44, -3.77
Total IP items Score		152	43.87	10.72	151	44.19	6.92	-.67	156	1.04	-.308	-2.36, 1.71

SRM = Self-Regulation Model, BIPQ = Brief Illness Perceptions Questionnaire, BAP = Beliefs About Problems (adapted BIPQ), CYP = Child/young person, CI = Confidence Interval. ** $p < .01$ significance value. Note: total items score -Some items removed from original BIPQ for this study therefore caution should be taken when reviewing overall mean in comparison to other studies.

¹ possible range -10 to 10, (-10= parent group more negative, 0 = matched 10 = child group more negative). [†] items negatively rated but converted for analysis, all items reported have 10 as a negative rating

Parental Expressed Emotion

A total of 92 parents completed the FMSS, a majority of which ($n = 53$) were classified as high expressed emotion (EE). Subcategories of EE are presented in Table 7.

Table 7. Expressed Emotion Categories

Overall EE category	Frequency ($n=92^1$)	Percent
Low	39	42.4
High	53	57.6
Subcategory		
Not Critical or EOI	39	42.4
Critical	26	28.3
EOI	16	17.4
Critical & EOI	11	12.0

EE= Expressed Emotion; EOI= Emotional Over Involvement, ¹ Analysis with EE completed with $n=92$ due to missing data for $n=64$

Outcomes

A summary of the means, standard deviations and ranges of the UEQ severity score and (child-rated and parent-rated) SDQ total difficulties score are reported in Table 8.

Table 8. Summary of independent variable (IP discrepancy score) and outcomes (UEQ severity, CYP-rated SDQ and parent-rated SDQ)

	N	Mean	SD	Range	Possible Range	Normative Sample Mean (SD)
UEQ Severity total	155	22.75	17.64	0, 81	0, 99	-
CYP-rated SDQ total	156	19.29	6.42	3, 33	0, 40	10.3 (5.2)
Parent-rated SDQ total	146	18.98	6.85	2, 34	0, 40	8.4 (5.8)
IP Discrepancy Score	156	-.67	12.90	-43.0, 34.0	-222, 222	-

UEQ Severity total = unusual experiences questionnaire severity score total, SDQ= Strengths and difficulties questionnaire total difficulties score, IP= Illness Perceptions. Normative sample range from general population aged 5-15 years (Meltzer et al., 2000).

Hypothesis 1) A greater discrepancy in illness perception will be associated with greater UEQ severity and greater CYP distress reported by both the CYP and parent on the SDQ.

Hypothesis one was tested using Pearson's R correlations. A significant correlation was found between IP discrepancy score and UEQ severity, such that a larger discrepancy was associated with increases in self-reported symptom severity ($r = 0.26, p < .01$). A significant correlation was found between IP discrepancy score and CYP-rated SDQ total difficulties score, such that a larger discrepancy was associated with higher levels of difficulty ($r = 0.31, p < .01$). No significant association was found between IP discrepancy score and parent reported SDQ total difficulties score ($r = .04, p = .61$).

As a sensitivity check, the analysis for UEQ severity, which was not normally distributed, was repeated using a Spearman correlation with similar results ($r_s = 0.29, p < .01$).

Secondary analysis

Secondary analyses were conducted to establish the amount of variance in outcomes accounted for by IP discrepancy scores, for the two outcomes for which a significant association was found (UEQ severity and CYP-rated SDQ score). Two separate linear regression analyses were conducted with each outcome as the dependent variable and IP discrepancy score as predictor variable, controlling for age and gender.

The model significantly predicted UEQ severity, ($R^2 = .08, F(3, 151) = 5.15, p < .01$), accounting for 8% of the explained variability in UEQ severity, whilst controlling for age and gender, both of which were non-significant in the model (Table 9). IP discrepancy score contributed significantly to the model ($\beta = .30, p < .01$). This means that for every unit increase in IP discrepancy the UEQ severity score will increase by .30 units, keeping age and gender constant.

The model significantly predicted SDQ score, ($R^2 = .13, F(3, 152) = 8.94, p < .01$) accounting for 13% of the variation. IP discrepancy score contributed significantly to the model ($\beta = .11, p < .01$) as did gender ($\beta = 2.58, p < .01$) but age did not ($\beta = .30, p = .16$). This means that for each unit increase in IP discrepancy the CYP-rated SDQ score will increase by 0.11 units, keeping age and gender constant.

The results of the regression indicated that both models explained a proportion of the variance in the respective outcomes with IP discrepancy scores as a significant predictor in both cases. Final predictive models were:

UEQ severity score = $7.52 + (.30 * \text{IP Discrepancy score}) + (.108 * \text{Age}) + (1.38 * \text{gender})$

SDQ score = $13.82 + (.11 * \text{IP Discrepancy score}) + (.30 * \text{Age}) + (2.58 * \text{gender})$

Table 9. Linear Regressions assessing the relationship between IP discrepancy and outcomes

		<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
UEQ Severity	IP Discrepancy Score	.30	.11	.22	2.62	.01**
	Age	1.08	.60	.15	1.81	.07
	Gender	1.38	2.95	.04	.47	.64
CYP-rated SDQ	IP Discrepancy Score	.11	.04	.22	2.80	.01**
	Age	.30	.21	.11	1.43	.16
	Gender	2.58	1.04	.20	2.48	.01**

IP= Illness Perception, *B*= unstandardized beta, *SE B*= standardised error beta, β = standardised coefficients beta, ***p* < .01 significance value.

Hypothesis 2) A greater discrepancy in illness perception will be found in the high EE group compared to the low EE group

This hypothesis was tested using between-group t-tests with IP discrepancy score as the dependent variable and EE categorisation as the independent variable. A significant relationship between EE status and IP discrepancy score ($t=-2.8, 90, p < .01$) was found. Those parents categorised as high EE had a larger IP discrepancy between themselves and their CYP than parents categorised as low EE. This test demonstrates a larger magnitude in IP discrepancy in the high EE group.

The discrepancy for each item on the IP measures was calculated and compared across high and low EE groups using independent samples t-tests (Table 10). To test for homogeneity of variance, Levene's test of equality of variances was calculated. These results are shown in Table 10 and where significant, indicating unequal variance, the adjusted calculations are reported.

Dyads with parents categorised as high EE had negative IP discrepancy means for five of the items; consequence, timeline, personal control, concern and emotional representation. Suggesting high EE parents, on average, reported more negative perceptions than their child on these items. A positive mean IP discrepancy on treatment control and coherence, suggest the CYP, on average, was more negative on these items than their parent, who was categorised as high EE. Dyads with parents categorised as low EE had negative IP discrepancy means for two of the items; personal control and concern. Suggesting low EE parents, on average, were more concerned than their child was about the problem and attributed more

personal control to the child than the child did themselves. The low EE group had positive IP discrepancy means for the other five items (consequence, timeline, treatment control, coherence and emotional representation). This indicates the low EE parents were more positive than their child on these items, with the CYP was reporting a more negative perception. When reviewing the mean difference between the high and low EE groups, there was a significant difference between the means on the consequence, timeline, treatment control, concern and emotional representation items. This shows that the high EE group were significantly more negative regarding consequences, timeline, concern and emotional representation and significantly more positive on treatment control than the low EE group.

Table 10. Independent samples t-tests on mean discrepancy scores of individual illness perception items of between high and low EE groups

		Mean discrepancy			Mean discrepancy Low EE									
		High EE group			group			Levene's Test				Mean	Std.	Error
SRM Dimension	Question Item	N	Mean	SD	N	Mean	SD	F	Sig.	t	df	Sig.	Diff	Diff
Consequence	1. How much does it affect your/your child’s life?	53	-2.02	3.44	39	.33	2.18	8.06	.01	4.00	88	.01**	2.35	.59
Timeline	2. How long do you think it will continue?	51	-.86	3.67	39	1.21	2.91	.30	.59	2.89	88	.01**	2.07	.72
Personal Control	3. How much control do you feel you/your child has over it?	52	-.90	4.29	38	-.37	3.52	1.22	.27	.63	88	.53	.54	.85
Treatment Control	4. How much do you think getting help can help with it?	51	4.67	3.79	39	2.15	3.47	.07	.80	-3.23	88	.01**	-2.51	.78
Concern	5. How worried are you about it?	52	-3.40	3.63	39	-1.59	2.80	5.71	.02	2.69	89	.01**	1.81	.67
Coherence	6. How well do you feel you understand it?	51	1.63	4.74	39	1.54	3.71	2.89	.09	-.10	88	.92	-.09	.92
Emotional Representation	7. How much does it affect how you feel?	51	-1.55	2.46	39	.38	2.41	1.04	.31	3.73	88	.01**	1.93	.52

SRM = Self-Regulation Model, EE = expressed emotion

** $p < .01$ significance value.

Hypothesis 3) The relationships between illness discrepancy and outcomes will be moderated by EE.

EE associations with outcomes

The final hypothesis was that the relationships between illness discrepancy and outcomes would be moderated by EE. Firstly, before assessing the moderating effect of EE on the relationships, analysis was completed to establish if EE was associated with outcomes (Table 11). Linear regression was used to test for this on each outcome (UEQ severity, CYP-rated SDQ, parent-rated SDQ) separately with the outcome as the dependent variable and EE as a predictor variable.

The model significantly predicted UEQ severity ($R^2 = .03$, $F(3, 97) = 4.14$, $p < .05$) accounting for 3% of the variation in UEQ severity score, with EE significantly contributing to the model ($\beta = -.6.87$, $p < .05$). However, the model was nonsignificant when repeated controlling for age and gender ($R^2 = .04$, $F(3, 95) = 2.36$, $p = .08$).

The model significantly predicted CYP-rated SDQ total difficulties score ($R^2 = .12$, $F(3, 96) = 5.34$, $p < .01$) accounting for 12% of the variance. However, gender significantly contributed to the model ($\beta = 3.45$, $p < .01$), age and EE did not. EE was not a significant predictor, even with gender and age removed from the model.

The model significantly predicted parent-reported SDQ total difficulties score ($R^2 = .14$, $F(3, 98) = 6.24$, $p < .01$) accounting for 14% of the variance. EE significantly contributed to the model ($\beta = 5.45$, $p < .01$), age and gender did not.

These results demonstrate that EE is a significant predictor for UEQ severity and parent-reported SDQ score but not CYP-rated SDQ, which appears to be significantly predicted by gender. Despite EE not being predictive of CYP-rated SDQ score or IP discrepancy not being predictive of parent-reported SDQ score, there is a possibility of a cross-over effect. This would mean that the main effect may not be significant, but that EE could still moderate the relationship with IP discrepancy. Therefore, a multiple regression with an interaction term of EE and IP discrepancy score was calculated for all three outcomes.

Table 11. Linear regression to assess relationship between EE and outcomes

		<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
UEQ Severity	EE	-5.48	3.54	-.16	-1.55	.13
	Age	.56	.79	.08	.71	.48
	Gender	4.69	3.56	.14	1.32	.19
CYP-rated SDQ	EE	.80	1.21	.07	.66	.51
	Age	.51	.27	.20	1.92	.06
	Gender	3.45	1.23	.28	2.81	.01**
Parent-rated SDQ	EE	5.45	1.31	.41	4.18	.01**
	Age	.05	.29	.02	.18	.86
	Gender	.22	1.31	.12	.17	.87

B= unstandardized beta, *SE B*= standardised error beta, β = standardised coefficients beta, ***p* < .01 significance value.

Moderating effect of EE on relationship between IP discrepancy and outcomes

Hierarchical multiple regression was run to understand the moderating effect of EE on the association between IP discrepancy and UEQ severity, CYP-rated and parent-rated SDQ total difficulties scores. To assess the increase in variation explained by the addition of an interaction term between EE and IP discrepancy to the main effects model, a regression analysis was conducted for each outcome individually. A stepped design was employed to assess the impact on the variance of the addition of the interaction term between EE and IP Discrepancy and then again with the addition of age and gender (Table 12).

EE did not moderate the effect of IP discrepancy on UEQ severity, as evidenced by a negligible increase in total variation explained (<1%) which was not statistically significant. Reviewing the steps of the model further showed when adding the interaction into the model, the significance of IP discrepancy contribution was reduced to non-significant.

EE did not moderate the effect of IP discrepancy on CYP-rated SDQ total difficulties score, as evidenced by the total variance explained increasing by 2% which was not statistically significant. The interaction was not significant but in review of the model, gender was significant ($B=2.85$, $p<.05$) and removed the significance of IP discrepancy. To understand this further, a Pearson's R correlation was conducted to evaluate the association between gender and the interaction of EE and IP discrepancy. Gender was significantly associated with the interaction ($r=.23$, $p<.05$).

EE did not moderate the effect of IP discrepancy on parent-reported SDQ total difficulties score. The total variance explained increased by 3%, in addition to the 17% explained by EE in step 1, but with a p value of 0.9 this was not statistically significant.

Table 12. Multiple Regression analysis of EE as a moderator on relationship between IP discrepancy score and outcomes (UEQ severity, CYP & parent reported SDQ)

Dependent		Independent								Adj.		F	
Variable	Step	Variable	B	SE _B	β	T	p	95% CI for B	R ²	R ²	F	ΔR^2	Change
UEQ Severity	Step 1	EE	-4.07	3.65	-.12	-1.12	.27	-11.33, 3.18	.09	.07	4.16	.09	4.16*
		IP Discrepancy	.32	.14	.24	2.25	.03*	.04, .61					
	Step 2	EE	-3.92	3.70	-.11	-1.06	.29	-11.26, 3.43	.09	.06	2.79	.001	.72
		IP Discrepancy	.40	.24	.29	1.62	.11	-.09, .88					
		EE*IP discrepancy	-.11	.30	-.06	-.37	.72	-.71, .49					
	Step 3	EE	-3.84	3.81	-.11	-1.01	.32	-11.42, 3.75	.10	.04	1.79	.007	.71
		IP Discrepancy	.31	.27	.23	1.16	.25	-.22, .85					
		EE*IP discrepancy	-.07	.31	-.04	-.21	.83	-.68, .55					
		Gender	3.14	4.04	.09	.78	.44	-4.9, 11.17					
		Age	.16	.87	.02	.19	.85	-1.56, 1.88					
CYP-rated total score	Step 1	EE	.38	1.28	.03	.30	.77	-2.17, 2.94	.09	.6	4.12	.09	4.12*
		IP Discrepancy	.14	.05	.30	2.82	.01**	.04, .24					
	Step 2	EE	.58	1.29	.05	.45	.66	-1.98, 3.13	.10	.07	3.37	.02	1.79
		IP Discrepancy	.24	.09	.49	2.76	.01**	.07, .40					
		EE*IP discrepancy	-.14	.11	-.23	-1.34	.18	-.35, .07					
	Step 3	EE	.85	1.29	.07	.66	.51	-1.71, 3.41	.17	.12	3.42	.06	3.23*
		IP Discrepancy	.14	.09	.30	1.59	.12	-.04, .32					

Dependent		Independent							Adj.		F		
Variable	Step	Variable	B	SE _B	β	T	p	95% CI for B	R ²	R ²	F	ΔR^2	Change
Parent-rated total score	SDQ	EE*IP discrepancy	-.10	.10	-.16	-.91	.37	-.30, .11					
		Gender	2.85	1.36	.23	2.10	.04*	.15, 5.56					
		Age	.31	.29	.12	1.09	.28	-.26, .88					
	Step 1	EE	5.75	1.35	.43	4.26	.001**	3.06, 8.43	.17	.15	9.07	.17	9.07**
		IP Discrepancy	.06	.05	.11	1.10	.27	-.05, .16					
	Step 2	EE	5.49	1.34	.41	4.09	.001**	2.82, 8.16	.20	.17	7.12	.03	2.86
		IP Discrepancy	-.06	.09	-.12	-.70	.49	-.24, .11					
		EE*IP discrepancy	.19	.11	.28	1.69	.09	-.03, .41					
	Step 3	EE	5.52	1.39	.41	3.96	.001**	2.74, 8.29	.20	.15	4.26	.003	.17
		IP Discrepancy	-.04	.10	-.08	-.46	.65	-.24, .15					
		EE*IP discrepancy	.18	.11	.26	1.57	.12	-.05, .40					
		Gender	-.85	1.47	-.06	-.58	.57	-3.77, 2.07					
		Age	.01	.31	.00	.04	.97	-.60, .63					

UEQ = Unusual Experiences Questionnaire, SDQ = Strengths & Difficulties questionnaire, IP = Illness Perception, EE = Expressed emotion, B = unstandardized regression coefficient, β = standardized regression coefficient, SE_B = Standard Error of B, ΔR^2 = R² change. ** = p<.01, *p<.05.

Understanding the role of EE

Graphs were created to visually inspect the relationship between the variables to better understand the moderating influence of EE. When reviewing the relationship between the line of best fit for IP discrepancy and UEQ severity score in relation to EE groups, the line is indicative of a linear trajectory for both groups (Figure 5).

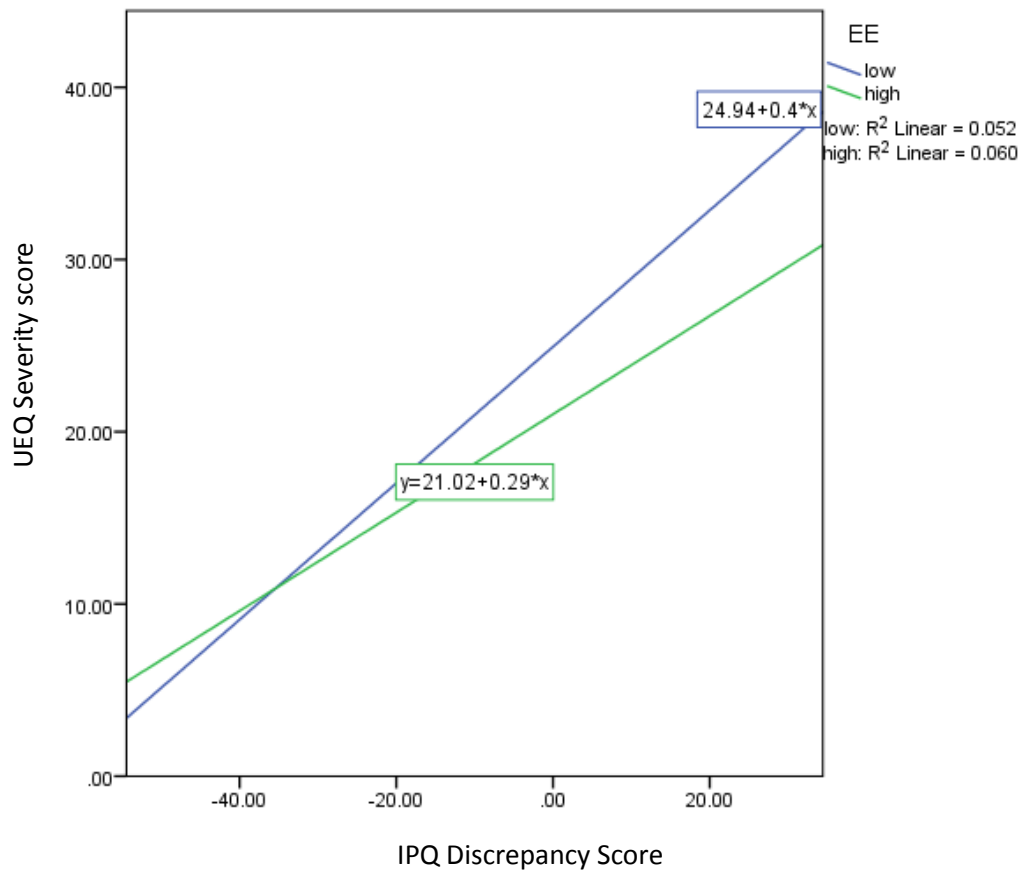


Figure 5. Graph to show the relationship between UEQ severity score and IP discrepancy in high and low EE groups.

The graph of CYP-rated SDQ score suggests a relationship between the variables, in as much as the lines of best fit converge at approximately zero discrepancy between parent and CYP. It appears that when there is no discrepancy between parent and CYP, EE categorisation does

not have an impact on the SDQ score, but as the IP discrepancy increases, either positively or negatively, there is larger variation in the SDQ score between high and low EE groups (Figure 6).

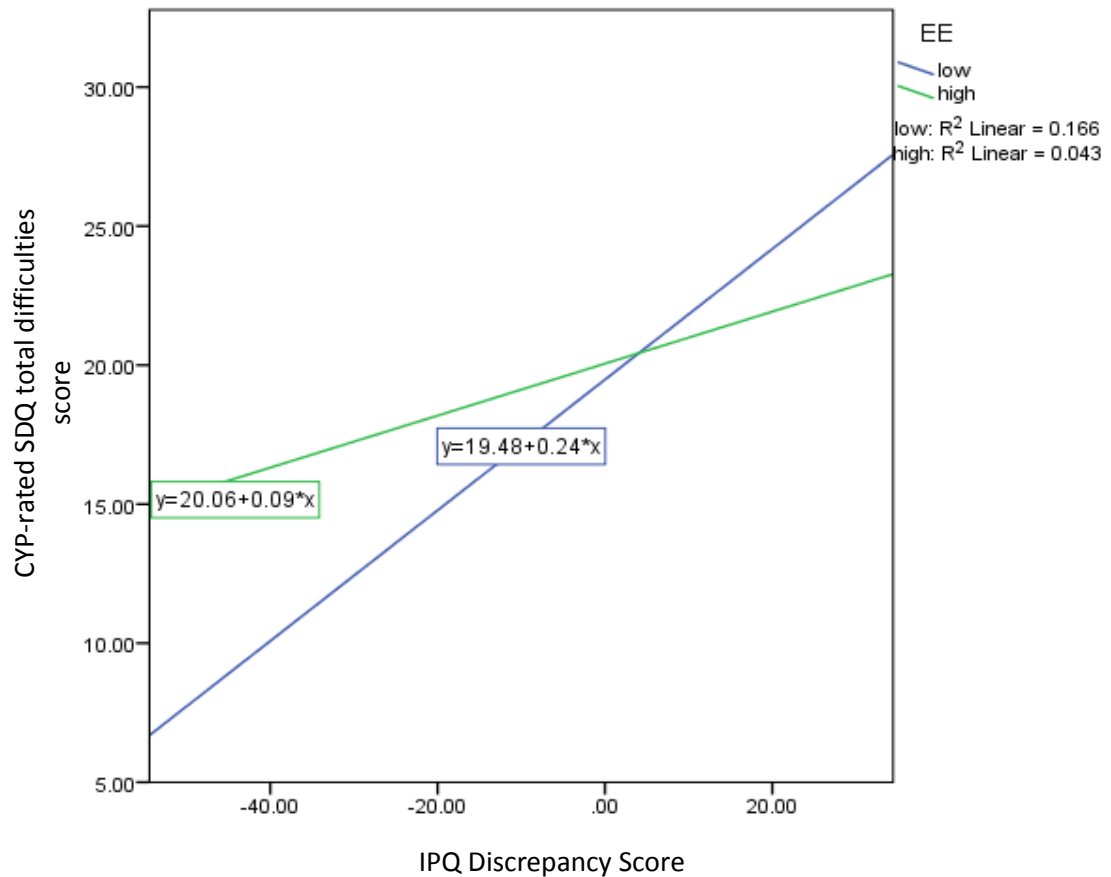


Figure 6. Graph to show the relationship between CYP-rated SDQ total difficulties score and IP discrepancy in high and low EE groups.

With a visual representation of the relationship between IP discrepancy and parent-rated SDQ scores in the graph (Figure 7), the trend towards significance with the interaction of EE and IP discrepancy is apparent. There does appear to be some form of relationship between the variables. This relationship would also account for the non-significant correlation between parent-rated SDQ and IP discrepancy as the groups would cancel each other out.

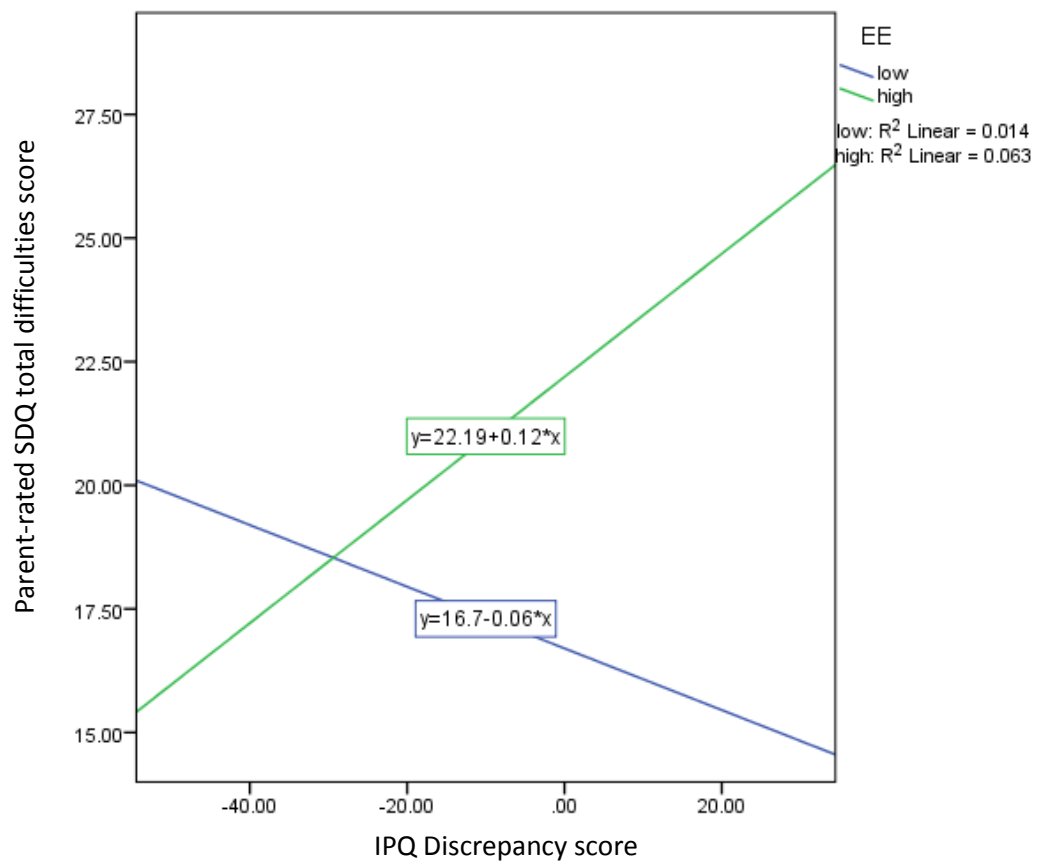


Figure 7. Graph to show the relationship between parent-rated SDQ total difficulties score and IP discrepancy in high and low EE groups

Discussion

Illness perceptions (IPs) have been shown to be associated with a range of clinical outcomes, for both physical health and mental health conditions (Baines & Wittkowski, 2013; Brown et al., 2001; Hagger & Orbell, 2003; Law et al., 2014). However, there is a dearth of research exploring IPs in CYP experiencing mental health conditions (as demonstrated by the systematic review reported earlier in volume). The available literature suggests negative IPs could have a significant influence on coping, quality of life and treatment outcomes in this population and therefore be an important potential treatment target (Gaziel et al., 2015; Imran et al., 2015; Moses, 2010, 2015; Munson et al., 2009, 2010).

The principle aim of the study was to expand the research field, by examining IPs of both the CYP and their parent and the influence of discrepancies between these representations in a mental health setting. Alongside this, the study aimed to add to the evidence base in relation to illness perceptions of CYP experiencing mental health conditions and the impact of illness

perceptions on outcomes. This is the first study to investigate discrepant illness perceptions between CYP and their parents in a mental health setting.

Three hypotheses were proposed in relation to IP discrepancies between CYP and their parents. These hypotheses were tested with baseline data from a large sample of CYP aged between 8 and 18 years old who had been referred to CAMHS services and recruited into a larger clinical trial (CUES pilot or CUES+). The first hypothesis was that a greater IP discrepancy would be associated with greater severity of unusual experiences (as reported by the CYP on the UEQ) and greater CYP emotional and behavioural problems (as reported by both the CYP and parent on the SDQ). The findings supported this hypothesis to some extent, with larger IP discrepancy predictive of CYP-rated emotional and behavioural problems and UE severity but not parent-rated emotional and behavioural problems.

The second hypothesis was that a larger IP discrepancy would be found in dyads of high EE parents compared to dyads of low EE parents (with EE rated by the FMSS). This hypothesis was confirmed by the results. Finally, it was hypothesised that the relationship between IP discrepancy and the outcomes (UE severity and both CYP-rated and parent-rated emotional and behavioural problems) would be moderated by EE categorisation. The results did not statistically support this hypothesis; however, a trend was found in further analysis of parent-reported SDQ scores, which suggests a possible relationship between EE, IP discrepancy and parent-reported emotional and behavioural difficulties.

Illness Perceptions of CYP with mental health conditions

CYP scores for all IP items averaged above the midpoint, suggesting negative illness perceptions with regards to consequences, timeline, personal control, treatment control, concern, coherence and emotional representation. To clarify, this means CYP endorsed the problem as: chronic, with a significant impact on their life, which they were concerned about and that affected them emotionally. These findings correspond with the small number of studies that have examined IPs in CYP with mental health difficulties previously (Imran et al., 2015; Munson et al., 2009). These findings are also consistent with the review of illness perceptions in adults, where mental health conditions were commonly viewed as cyclical and chronic, with serious negative consequences (Baines & Wittkowski, 2013). Overall CYP endorsed that they did not have control over the problem and getting help would not be beneficial. In relation to treatment control, the mean was only just above the midpoint, which would suggest it was not a strongly held belief. In this study, CYP endorsement of negative IPs (higher IP item total) was strongly associated with an increase in CYP reported emotional and behaviour problems and UE severity. Parent IP endorsement was strongly

associated with their report of the emotional and behavioural problems and to a lesser extent, but still significant, to the CYP report of SDQ, however, it was not associated with UE severity. These findings demonstrate that negative IPs are associated with poorer outcomes. These findings are a striking insight into the IPs of CYP being referred into CAMHS, which highlight the potential scale of the problem and emphasise the need for intervention and the value of addressing negative IPs as part of this.

Discrepant Illness perceptions between parent and CYP

When comparing the overall means scores of both parents and CYP, perception of timeline was the only item where the groups were not significantly different. Both parents and CYP endorsed the problem as enduring/chronic. This is conflicting with the findings within the adult psychosis literature which found carers were more pessimistic than patients regarding timeline (Kuipers et al., 2007). Parents were significantly more negative with regards to the impact of the problem on the child's life which supports the same finding in adults with psychosis, with carers being more pessimistic about the consequences of the condition (Kuipers et al., 2007).

Parents also reported significantly higher levels of concern, with a very high average, and greater emotional response towards the problem. Interestingly, the discrepancy between the concern of parents and CYP was quite large, suggesting CYP saw the problems as considerably less concerning. Parents were, however, more positive regarding treatment control, demonstrating that parents perceive treatment to be more potentially helpful than CYP, with treatment control having the largest discrepancy between groups for all the IP items. Within CAMHS services it is common for the parent or another adult to have made the referral for the CYP (rather than access to care being by self-referral) and this may account for higher parental perception that treatment can help. Parents also attributed more personal control to the child. Despite having significantly different scores on individual items, the overall IP item total was similar between the parent and CYP groups. This is likely due to the cancelling effect of some items being perceived more positively and some more negatively by the parents. It is worth noting that the IP discrepancy range was broad with some dyads having a discrepancy score in excess of 30 in both directions (parent more negative and positive). This is consistent with Quiles Marcos et al. (2009) who found caregivers of young adults with an eating disorder to have broadly similar IPs to their relative. However, the finding that parents endorsed a more negative perception on individual items was also similar to previous findings, in particular CYP with diabetes (Gaston et al., 2012). However, this was not consistent with Lobban et al. (2006) finding of a more negative

perception overall. These contrasting results may indicate that the effect of IP discrepancies is moderated by different illness characteristics and it may be that different mental health difficulties will have diverse patterns of discrepancy between parent and CYP (Heijmans et al., 1999).

CYP emotional and behavioural difficulties

Average levels of child emotional and behavioural difficulties were elevated in both parent and CYP reports on the SDQ compared to the normal population. Both groups reported an average score in the high range (above 17 for parents and above 18 for CYP), with 67% of CYP and 63% of parents reporting a score above this compared to 10% of the population (Goodman et al., 2000). These scores indicate high levels of emotional, social and behaviour difficulties that are likely to reflect clinically significant problems. However, this finding would be expected within a clinical sample who have been referred to CAMHS services.

There are no normative or classification scores for the UEQ, however the mean UEQ severity score was double that reported by Ames et al. (2014) in a small sample of CYP's referred to tier 2 CAMHS (mean 11.10, S.D = 12.44). Again, this higher score would be expected as the CYP for this study included participants who were recruited from services treating more severely unwell presentations, and selected due to their reports of UEs.

Expressed Emotion

The way in which the main caregiver emotionally responds towards the individual with the health condition (EE) has also been shown to have a significant impact on recovery and relapse in the adult population, with high EE reliably associated with increased rates of relapse (Barrowclough 2000).

The majority of parents within the study were rated as high EE but the groups were relatively even (58% classified as high EE). The proportion of high EE parents was considerably higher than that of a non-clinical sample of mothers of children aged between 8-11 years, with 77% categorised as low EE and 23% as high EE ($n=64$, Han & Shaffer, 2015). However, this is likely to be representative of the clinical sample and previous studies of children with UEs have found elevated levels of EE (O'Brien et al., 2006; Polanczyk et al., 2010). This contrasts with the studies examining illness perception discrepancies in adults, which have reported a majority of carers being categorised as low EE. These studies have commented on the limited number of high EE carers as a limitation to their analysis (Kuipers et al., 2007; Lobban et al., 2006). This may be due to parents being categorised as emotionally over-involved more readily by the nature of the dependency of the child on the parent.

Hypothesis 1) A greater IP discrepancy will be associated with greater UE severity and greater emotional and behavioural problems

The hypothesis was partially supported in that there was an association between IP discrepancy and UEQ severity and CYP-rated SDQ score. However, there was no association between IP discrepancy and parent-reported SDQ score. These results support that larger discrepancies in illness perceptions were associated with greater symptom severity and greater emotional and behavioural problems as reported by the CYP. In addition to this, IP discrepancy significantly predicted UEQ severity score and CYP-rated SDQ score, accounting for 8% and 13% of the variance respectively, even when controlling for the age and gender. An association between mental health IP discrepancies and outcomes supports the previous findings with adults; that larger IP discrepancies are associated with worse outcomes (Kuipers et al., 2007; Lobban et al., 2006). This finding is also in line with physical health results: Gaston et al. (2012) found an association between IP discrepancies and clinical outcomes in CYP with diabetes. In contrast, Quiles Marcos et al. (2009) had previously found that young adults with an eating disorder who agreed with their relatives negative IPs, had worse outcomes than those who had discrepancies in IPs. This was not the case in the current sample, however, due to the limited research in IP discrepancies it is not possible to conclude if this is due to the different effects of IP discrepancy in different health conditions. It is speculated that one possible cause for the significant association between IP discrepancies and CYP-reported measures (of both emotional and behavioural problems and UE severity) is that CYP were more aware of the discrepancy between their perceptions of the problem and their parents and this in turn resulted in greater perceived problems. However, this is speculative and cannot be confirmed. The difference in association with the SDQ scores highlights that having two informants on the same measure can result in different reports. Although both measures have been shown to be reliable and valid, this outcome highlights the importance of obtaining multi-informant SDQ ratings, as recommended by Goodman et al. (2000). This provides the clinician and researcher with richer information which may not be consistent.

Hypothesis 2) A greater discrepancy in illness perception will be found in the high EE group compared to the low EE group

This hypothesis was fully supported, with the results demonstrating that IP discrepancy differed according to EE group: CYP and high EE parents reported larger IP discrepancies than

CYP and low EE parents. This result is in line with the findings by Lobban et al. (2003) in adults with psychosis, which found a greater IP discrepancy between the high EE relative and the patient.

It was also possible to establish, by calculating mean discrepancies across the IP items, that the high EE parents were significantly more negative regarding consequences, timeline, concern and emotional representation and significantly more positive on treatment control than low EE parents. Interestingly, there was not a significant difference between low and high EE groups on personal control. This dimension has previously been associated with frustration and anger if the relative perceives that the individual can control their behaviour, an emotional response you may expect to be displayed by an individual categorised as high EE (Lobban et al., 2003).

Hypothesis 3) The relationships between illness discrepancy and outcomes will be moderated by EE.

In order to examine the moderating influence of EE, the association between EE and the outcomes (UE severity and emotional and behavioural problems) first needed to be established. These results showed that EE was not associated with UEQ severity or CYP-rated SDQ score. EE not being related to CYP-rated SDQ or UEQ severity would indicate that EE does not influence the CYPs perceptions of their symptoms or their emotional and behavioural problems. This does not necessarily contradict previous findings that EE was associated with worse outcomes. It could be argued that the self-report measures used do not objectively observe whether EE influences outcomes, nor does the study observe this impact overtime. EE did initially predict UEQ severity; however, this association was not significant when age and gender were added to the model. Both age and gender were found to correlate with UEQ severity, however they were not predictive in the model. The UEQ emphasises the perceived meaning of unusual experiences, rather than just specifically their presence or absence, and therefore it is possible that this perception may be influenced by gender (Garety et al., 2007; Morrison & Baker, 2000). EE was associated with parent-reported SDQ score, accounting for 14% of the variance explained, irrespective of controlling for age and gender. This result suggested that the parent's emotional response towards their child is predicative of their perception of their child's difficulties. However, this could be due to a high EE parent perceiving and reporting greater problems rather than the CYP objectively experiencing worse emotional or behavioural problems.

Despite IP discrepancy and EE not being associated with all the outcomes under investigation the interaction of EE and IP discrepancy was examined to ensure no cross-over effect

between variables. However, EE did not significantly moderate the effect of IP discrepancies between parent and CYP on UE severity or emotional and behavioural difficulties.

Although the interaction between EE and IP discrepancy was not statistically significant, there does appear to be some form of relationship between EE, IP discrepancy and reported emotional and behavioural problems. The model was also not significant for parent-reported SDQ but there was a trend, as the interaction did explain a further 3% of the variance in addition to the 17% explained by EE alone. Reviewing the variables visually via graphs implied some form of relationship was occurring. It appeared EE groups differed in the way IP discrepancy influenced the parent-reported SDQ score and which way the discrepancy goes (i.e. if parent or child was more negative). This relationship requires more investigation, as the result may not have met significance due to the sample size and would benefit from further testing with a larger sample. This contrast in groups could suggest that when determining the appropriate intervention EE categorisation needs to be considered if both groups respond differently, depending on who perceives the problem as more negative (parent or CYP). For example, improving the perception of the illness in parents categorised as high EE, to the extent that the parent is more positive, could worsen their perception of the child's difficulties.

There also appeared to be a relationship on the graph for child-reported SDQ, with the lines of best fit for both high and low EE groups converging when there was no IP discrepancy. There was a larger variation in SDQ score, between high and low EE groups, as the IP discrepancy increased. The CYP in the low EE dyads reported increased emotional and behavioural problems, as they (CYP) reported an increased negative perception, compared to the high EE group. Whereas, when the parent reported the increased negative perception, the CYP in the low EE dyads reported lower emotional and behavioural problems, than the CYP in the high EE dyads. Gender was shown to explain a proportion of the variance in CYP-rated SDQ score and was also shown to be associated with the interaction between EE and IP discrepancy. This relationship requires further investigation with separate analysis of sexes to be fully understood.

Clinical implications

Research is attempting to understand the trajectory of mental health and psychosis development by investigating UEs in CYP, in order to examine how early in this trajectory we can meaningfully understand the risk factors associated with the later development of severe mental illness. Adolescence is a key stage for the onset of mental health difficulties, and the development of future mental health vulnerabilities (Poulton et al., 2014). Therefore, this is

a crucial time for early intervention to ensure the risks to CYP are reduced as best as possible, which is recognised in NICE guidelines (CG155, 2013). The current findings indicate that IPs are associated with outcomes and therefore this is an area that demands consideration as part of assessments and interventions. It is a feasible assumption that current cognitive behavioural therapy interventions could relatively easily incorporate addressing IPs and provide the psychoeducation required depending on those IPs negatively endorsed. However, clinical trials of this adapted intervention would be required to examine its additional value to CBT as standard. Both CYP and their parents perceived the mental health difficulties as negative and the majority of dyads had discrepant IPs. With both negative IPs and IP discrepancies predicting poorer outcomes, it is possible that this is a factor to address in wider, family based therapeutic interventions. These could be family interventions that are CYP specific aimed at improving IPs and promoting concordance of IPs in families. However, it is also possible for this to be a more informal intervention with frontline staff (e.g. care workers) who could assess IPs within families and offer psychoeducation to normalise families' perceptions and promote congruence. The data also indicates EE as a factor in the relationship, with IP discrepancy greater in high EE dyads and CYP exposed to high EE having worse emotional and behavioural problems, as reported by the parent. This supports the cognitive model of caregiving which recommends different therapeutic intervention depending on relationship style and level of EE (Kuipers et al., 2010). Family intervention for psychosis is very effective at reducing levels of EE, relapse and readmission rates (Claxton et al., 2017; J Onwumere, Bebbington, & Kuipers, 2011) however the mechanisms of how the intervention achieves this is unclear and part of this may be by adjusting illness perceptions of the family to be more accurate and more aligned. Drawing on cognitive models of caregiving and the early intervention initiatives, may inform early intervention for CYP that addresses psychosis risk in the context of mental health risk in general.

Limitations

Research limitations

The first limitation of the study is the cross-sectional nature of the design, which means it is not possible to draw inferences regarding causation. Previous studies have found EE to be predictive of children's problem behaviour four years on, however, it is also possible that EE has an exacerbating or maintaining role, rather than a casual one (Goldberg-Arnold, Fristad & Gavazzi, 1999; Bolton et al., 2003). Findings from the current study may imply that high EE

categorisation and a larger IP discrepancy result in increased UEQ severity and child emotional and behavioural problems but equally it could be these variables that are causal. For example; whether high EE results in IP discrepancies and poorer outcomes or poorer clinical outcomes lead to discordant illness perceptions and parents become highly expressive as a result, or if there is a more complex bi-directional relationship occurring is still unclear at this stage. However, these variables are influencing one another, and high EE interactions are one way this cycle may be perpetuated. Understanding the causal direction is crucial to determine what factors need to be targeted in early interventions and to validate the clinical value of targeting IPs. Causality could be further explored with the data collected at later timepoints within CUES pilot and CUES + to examine if any significant change is observed in the variables of interest throughout the intervention.

Another limitation, that reduces the reliability of the findings, is that UEQ severity scores were not normally distributed and therefore results should be treated with caution.

In relation to other confounding variables that may influence the reliability of the results, demographic variables of age and gender were found to be significantly associated with some variables of interest and gender removed the predictive significance of IP discrepancy on CYP-rated SDQ score. Therefore, further analysis needs to be completed to understand and unpick the involvement of these variables. The excluded participants, due to missing data, were also found to be significantly different in relation to ethnicity and age. This could therefore mean the sample were not representative and the results influenced which may require further exploration. However, the age difference, although statistically different, did not appear to be clinically significant as the mean age for both groups was within the CYP's 13th year. A variable that was not able to be considered in this study was the socioeconomic status of the participants. This information would be beneficial in addressing how different socioeconomic backgrounds report illness perceptions or rates of EE and to establish if there is any variation in the results. Research findings demonstrate socioeconomic status as a vulnerability factor for mental health problems, (World Health Organisation, 2012) therefore this is a variable in need of exploration in future research. Who referred the child may also have influenced the results, as CYP who had been referred by their parents or another professional may not perceive or report any problems and therefore could be completing IP questions based on another concern/problem they perceive to have, which was not the referral reason and unrelated to their mental health.

EE was categorised using the FMSS, which has been shown to be reliable but is not the 'gold standard' of CFI, which may be a more stringent measure. The proposed theories also

assume that the way in which parents speak about their child in the FMSS reflects their interactions with the child on a day-to-day basis. A higher number of parents were classified as high EE, in comparison to adult literature. This is possibly due to parents being categorised as emotionally over-involved more readily due to these behaviours being normative for parents and not necessarily negative (McCarty, Lau, Valeri, & Weisz, 2004). It is also worth considering that O'Brien et al. (2006) reported that higher levels of EOI was associated with reductions in adolescent symptoms and enhanced social functioning. This suggests the possibility that EOI may function differently at different developmental stages and may be developmentally appropriate in adolescence. Therefore, it may be more beneficial in CYP studies to examine the subcategories of EE as this may provide a more accurate representation in this population. Future research is needed to test the extent to which EE relates to actual parenting behaviour and aspects of the parent-child relationship.

Future Research Recommendations

This study has added to the relatively small field of CYP illness perceptions and the impact of IP discrepancies in mental health generally. Due to this field being small there is extensive avenues for further research. As has been critiqued, with this study being cross-sectional, causality cannot be determined. Longitudinal research would be necessary to consider the casual effect of IP discrepancy and EE on outcomes over time. Interventional studies could also examine the changes in EE or IP discrepancy due to intervention. Replicating the interaction between EE and IP discrepancy in a larger sample, would increase power to confirm definitively whether EE does or does not moderate the relationship between IP discrepancy and outcomes, accounting for demographic variables. A challenge with this, however, would be recruitment and due to the variance acknowledged within different health conditions caution should be taken on recruiting a heterogenous sample. For the relationship between parent-reported SDQ and high EE to be disentangled and understood further, longitudinal research would be needed. This could determine if reports of perceived emotional and behavioural difficulties altered independently of high EE or whether both decreased with intervention. Another alternative would be to also use teacher reported SDQ. There is also the avenue of examining IPs endorsed in other mental health difficulties, whether IP discrepancies exist and whether they are associated with the same outcomes. Another consideration would be the influence of IPs on other clinical outcomes, such as adherence, which has been shown to be associated with IPs in adult mental health.

Conclusion

This study set out to understand the role of discrepant IPs between CYP with UEs and their parents, and the impact of EE on this relationship, with a view to informing the development

early interventions targeting CYP with an at-risk mental state. This study was the first to examine IPs in CYP in the context of UEs. Overall the study has provided: further information in relation to the IPs endorsed by CYPs with mental health difficulties, evidence of associations between negative IPs and poorer outcomes, evidence that a greater IP discrepancy between parent and CYP was associated with greater UE severity and greater emotional and behavioural problems (hypothesis 1) and evidence of greater IP discrepancies in high EE dyads compared to the low EE dyads (hypothesis 2). The findings indicate that EE does not moderate the relationship between IP discrepancy and the outcomes, however there does appear to be some form of relationship that requires further investigation. The findings indicate that negative IPs and discrepancies in IPs between parent and CYP are indicative of poorer outcomes. High EE parents were also likely to have greater discrepancies between their IPs and their child's in comparison to low EE parents. Despite EE not moderating the effect of IP discrepancy on outcomes, there does appear to be some interaction. These findings indicate that interventions addressing and adapting IPs of both CYP and parents would improve patient outcomes. With the potential for continued UE to lead to risk of further mental health (Asher et al., 2013) IPs are a factor that need to be considered within early interventions for CYP with an at-risk mental state, to strive to reduce the prevalence of mental health conditions in CYP that can persist into adulthood.

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Appendices

Appendix 1. Beliefs About Problems Questionnaire

Beliefs about problems v1 270914 (Bradley, 2013)

Is anything bothering you or upsetting you at the moment?

☐ Yes

☐ No

If yes, what would you say is the main thing that is bothering, upsetting or difficult for you right now?

If no, what would you say is the main reason you have come to this team?

Thinking about EITHER the thing that is bothering you OR the reason you came, please answer the questions below. Circle the number that comes closest to what you think.

1. How much does it affect your life?

0 1 2 3 4 5 6 7 8 9 10
doesn't affect at all severely affects my life

2. How long do you think it will continue?

0 1 2 3 4 5 6 7 8 9 10
a very short time forever

3. How much control do you feel you have over it?

0 1 2 3 4 5 6 7 8 9 10
no control at all lots of control

4. How much do you think getting help can help with it?

0 1 2 3 4 5 6 7 8 9 10
not at all helpful extremely helpful

5. How worried are you about it?

0 1 2 3 4 5 6 7 8 9 10
not at all worried extremely worried

6. How well do you feel you understand it?

0 1 2 3 4 5 6 7 8 9 10
don't understand at all understand very clearly

7. How much does it affect how you feel? (e.g. makes you angry, scared or upset)?

0 1 2 3 4 5 6 7 8 9 10
not at all extremely

8. How much do you think talking therapy can help with it?

0 1 2 3 4 5 6 7 8 9 10
not at all helpful extremely helpful

9. How much do you think changing the way you think or the way you do things can help with it?

0 1 2 3 4 5 6 7 8 9 10
not at all helpful extremely helpful

Beliefs about problems v1 270914

10. How much do you think looking at things differently could help with it?

0 1 2 3 4 5 6 7 8 9 10
not at all helpful extremely helpful

11. Please list in rank-order the three most important things that you think caused it (made it happen).

The most important causes for me are:-

i. _____

ii. _____

iii. _____

Still thinking about EITHER the thing that is bothering you OR the reason you came, please answer the questions below. Circle the number that comes closest to what you think.

12. Is it OK and safe or is it worrying or dangerous?

5	4	3	2	1
Completely worrying or dangerous	Mostly worrying or dangerous but not completely	Mix of worrying or dangerous and OK or safe OR neither is true	Mostly OK and safe but not completely	Completely OK and safe

13. Is it stronger than you and hard to handle, or are you stronger and can handle it?

5	4	3	2	1
Completely stronger than me and hard to handle	Mostly stronger than me and hard to handle but not completely	Mix of stronger than me and less strong than me OR neither is true	Mostly me stronger and I can handle it but not completely	Completely me stronger and I can handle it

14. Is it caused by something to do with you, or is it caused by something or someone else?

5	4	3	2	1
Completely something or someone else	Mostly something or someone else but not completely	Mix of me and something or someone else OR neither is true	Mostly something to do with me but not completely	Completely something to do with me

15. Is it something's or someone's fault, or does it just happen?

5	4	3	2	1
Completely something's or someone's fault	Mostly something's or someone's fault but not completely	Mix of something's or someone's fault and just happening OR neither is true	Mostly just happens but not completely	Completely just happens

16. Is something or someone doing it on purpose, or is it accidental /something they can't help?

5	4	3	2	1
Completely on purpose – they meant it	Mostly on purpose but not completely	Mix of on purpose and accidental OR neither is true	Mostly not on purpose but not completely	Not at all on purpose – it is an accident, or they can't help it

Beliefs about problems v1 270914

Still thinking about EITHER the thing that is bothering you OR the reason you came, please answer the questions below. Circle the number that comes closest to what you think.

17. People ignore me or take me less seriously because of it

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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18. I am annoyed at myself for having it / it happening

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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19. I avoid trying to be friends with people who haven't had the same thing happen, in case they wouldn't want to be friends with me

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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20. I don't mix with friends as much as I used to because it might make me look or behave 'weird'

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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21. It has spoiled my life

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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22. Others think that I can't do very much because of it

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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23. I need others to make more decisions for me because of it

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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24. People who it has happened to are usually violent

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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25. People who it happens to cannot live a good, happy life

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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26. I would feel OK being out with a person who has obviously had the same thing happen

Strongly Disagree	Slightly Disagree	Don't Know	Slightly Agree	Strongly Agree
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BAP

Appendix 2. Unusual Experiences Questionnaire
YP Unusual Experiences v1 270914

Unusual Experiences 1

Circle the answers that apply to you.

1. Some people believe that their thoughts can be read. Have other people ever read your thoughts? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
2. Have you ever believed that you were being sent special messages through the television? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
3. Have you ever thought that you were being followed or spied upon? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
4. Have you ever heard voices that other people could not hear? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
5. Have you ever felt that you were under the control of some special power? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	

UNUSUAL EXPERIENCES

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6. Have you ever known what another person was thinking even though that person wasn't speaking? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
7. Have you ever felt as though your body had been changed in some way that you could not understand? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
8. Do you have any special powers that other people don't have? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
9. Have you ever seen something or someone that other people could not see? If true:	Not true		Somewhat true		Certainly true
How often has it happened over the last 2 weeks?	Not at all	Only once	2-4 times	5 or more times	
How much has it upset you?	Not at all	Only a little	Quite a lot	A great deal	
How much has it made things hard at home or school?	Not at all	Only a little	Quite a lot	A great deal	
10. If you have not had any of these experiences in the last 2 weeks, have you had any of them in the last year?	Not true		Somewhat true		Certainly true

UNUSUAL EXPERIENCES

Unusual Experiences 2

Of the experiences we have talked about, which is the main or most upsetting one?

- ☐ Believing that your thoughts can be read.
- ☐ Believing that you are being sent special messages through the television.
- ☐ Thoughts of being followed or spied upon.
- ☐ Hearing voices that other people cannot hear.
- ☐ Feeling that you are under the control of some special power.
- ☐ Knowing what another person is thinking even though that person isn't speaking.
- ☐ Feeling as though your body has been changed in some way that you cannot understand.
- ☐ Having special powers that other people don't have.
- ☐ Seeing something or someone that other people cannot see

Now thinking about this unusual experience, please answer the questions below.

1. Do you think it is OK and safe or does it seem worrying or dangerous?

5	4	3	2	1
Completely worrying or dangerous	Mostly worrying or dangerous but not completely	Mix of worrying or dangerous and OK or safe OR neither is true	Mostly OK and safe but not completely	Completely OK and safe

2. Does it feel stronger than you and hard to handle, or are you stronger and can handle it?

5	4	3	2	1
Completely stronger than me and hard to handle	Mostly stronger than me and hard to handle but not completely	Mix of stronger than me and less strong than me OR neither is true	Mostly me stronger and I can handle it but not completely	Completely me stronger and I can handle it

3. Is it caused by something to do with you, or is it caused by something or someone else?

5	4	3	2	1
Completely something or someone else	Mostly something or someone else but not completely	Mix of me and something or someone else OR neither is true	Mostly something to do with me but not completely	Completely something to do with me

4. Is it something's or someone's fault, or does it just happen?

5	4	3	2	1
Completely something's or someone's fault	Mostly something's or someone's fault but not completely	Mix of something's or someone's fault and just happening OR neither is true	Mostly just happens but not completely	Completely just happens

5. Is something or someone doing it on purpose, or is it an accident and something they can't help?

5	4	3	2	1
Completely on purpose – they meant it	Mostly on purpose but not completely	Mix of on purpose and accidental OR neither is true	Mostly not on purpose but not completely	Not at all on purpose – it is an accident, or they can't help it

UNUSUAL EXPERIENCE Appraisals

Appendix 3. Strengths and Difficulties Questionnaire

Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with others (food, games, pens etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am usually on my own. I generally play alone or keep to myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make other people do what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on me or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others (parents, teachers, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get on better with adults than with people my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I'm doing. My attention is good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your signature

Today's date

Thank you very much for your help

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Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

Child's Name

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature

Date

Parent/Teacher/Other (please specify:)

Thank you very much for your help

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